

**Losing an Identical Co-twin in Older
Adulthood:
An Interpretative Phenomenological Analysis**

Miriam Dookhun

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Student Number: u0928278

Abstract

This is a qualitative study exploring the experience of the loss of an identical co-twin in older adulthood. Ten participants were recruited for the study through the biggest twin registry in the United Kingdom (UK): TwinsUK. All ten were interviewed, and transcripts of the interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Five key themes, referred to in this study as ‘master themes’, emerged from the analysis: The Twin Relationship, Embodiment, Separation, Preservation of a Connection, and Grief Comparisons. The analysis highlighted two central ideas: embodiment and identity.

The study aligns with several existing frameworks for understanding twins and bereavement, including a unit identity and feelings of a loss of part of the self with the bereavement. The study also supports ideas about embodied grief, continuing bonds with the deceased, and co-twin loss being worse than other kinds of losses.

Some distinctive contributions to Counselling Psychology and the understanding of bereavement are seen, for example a violent dimension within embodied grief is highlighted. In addition there are aspects of continuing bonds with the deceased in co-twin relationships that differ from continuing bonds in other relationships.

Furthermore, co-twin loss was felt by some participants to be worse than other types of losses. This last finding has also arisen in previous research, and this study sheds some light on why research participants have felt this way.

The study suggests that it is important for practitioners to gain insight into this particular dimension of loss. This may help lone twin clients feel better understood and heard, and better supported in the management of the loss. This study may also contribute to the general area of grief management through engagement with ideas of identity and embodiment as aspects of the experience of loss. Finally, potential areas for further study in this field are discussed.

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Table 1.2: Master Themes and Subthemes

Abbreviations

DZ Dizygotic (Non-Identical)

GEI Grief Experience Inventory

GIS Grief Intensity Scale

IPA Interpretative Phenomenological Analysis

MZ Monozygotic (Identical)

UEL University of East London

UK United Kingdom

Glossary

Co-twin: a twin's twin

Dizygotic or Fraternal twins: non-identical twins

Lone twin or Twinless twin: a twin whose co-twin has died

Monozygotic twins: identical twins

Introduction

This study has been developed and carried out within the discipline of Counselling Psychology, yet this is a discipline with an evolving identity. It has primarily been influenced by thinkers such as Wilhelm Wundt and William James, who were interested in consciousness and understanding subjective experience (Strawbridge & Woolfe, 2010). Others, including Maslow, Rogers and May, also played a role: they contributed to Counselling Psychology's humanistic values-base and also focussed on subjective experiences (Strawbridge & Woolfe, 2010). William Dilthey linked the term 'human science' to a theory of understanding experience (Strawbridge & Woolfe, 2010, p.9) and held an influential role in the development of research into subjective experience (Rennie, 1994). James and Dilthey argued that a true human science had to be based on interpretation and analysis of meaning (Rennie, 1994). It is in this human science perspective that Counselling Psychology is rooted (Strawbridge & Woolfe, 2010). It could be argued that in this way Counselling Psychology brings counselling back to psychology. With an emphasis on psychological theory, Counselling Psychologists are encouraged to pay close attention to meaning (Strawbridge & Woolfe, 2010). It is within this framework that the current research has been conducted.

To understand the purpose of this research, its goals and methods (Ponterotto, 2005), and to evaluate it (Madill, Jordan & Shirley, 2000), it is important to acknowledge the philosophical framework it is coming from (Ponterotto, 2005). Its epistemological position is phenomenological, meaning that subjectivity is valued, together with the view that personal reality is constructed (Ponterotto, 2005). What it is to know, what knowing involves and its limits depend on lived experiences and the accounts that are

given of them (Larsson, Brookes & Loewenthal, 2012). The current study is an attempt to place value on individual experiences and perspectives, an approach that is encapsulated by both the philosophical roots of Counselling Psychology and this research's epistemological position. Furthermore, Morrow (2005) suggests that qualitative research methods are closely linked to the practice of Counselling Psychology, and the current study advocates for the use of one such method, IPA, the philosophical roots of which are also compatible with the foundation and practice of Counselling Psychology. IPA strives to give voice to and make sense of the concerns of participants, and to contextualise their accounts from a psychological perspective (Larkin, Watts & Clifton, 2006). It has been chosen here because it is important to conduct research as a Counselling Psychologist that is compatible with Counselling Psychology's values, and that bridges theory and practice so that the research is also meaningful to clinicians in practice.

This thesis examines the experience of losing an identical co-twin in older adulthood. Approximately 3% of the general population are twins (Withrow & Schwiebert, 2005) and their special unity (Ortmeyer, 1970) and bonds have aroused curiosity for many years (Bryan, 1983). However surprisingly, the severing of this bond through death has not been studied extensively (Withrow & Schwiebert, 2005).

Although grief is thought of as a universal experience, definitions of it vary widely (Howarth, 2011). For example, Dunn and Civitello (2009) noted that it is the emotional response to death, while others have expanded this observation further: 'It incorporates diverse psychological (cognitive, social-behavioural) and physical (physiological-somatic) manifestations' (Weiss, 2008, p.6). Grief is also viewed

differently cross-culturally: for example some cultures view the dead as sacred, others as ancestors (Klass & Goss, 1999). In Japanese culture, the death of a family member leads to a new family membership as the deceased becomes an ancestor and takes on a different role from that held while living (Klass & Goss, 1999). In Western cultures grief is viewed as a negative emotion, and it has been characterised by general theories of emotion as a feeling that is socially constructed, grounded in the person's perception of the situation (Charmaz & Milligan, 2006). Behavioural codes for the expression of grief also vary across cultures: Western societies' rules generally prescribe that women can cry but men are not expected to (Harris, 2010); Egyptian-Bedouin culture prescribes that, in public, people should include denial, blame, anger and indifference in their reactions to a death whereas, in private, acceptable responses include excessive sadness and pain expressed through song-poems (Abu-Lughod, 1985).

Religions also view the dead in different ways, for example Buddhists believe in rebirth, and the grieving are encouraged not to cry so that they do not cause the dead excessive regret, as the dead are thought to continue relating to the living through consciousness, and it is consciousness that is reborn (Klein, 1991a). In Islam, mourning is not encouraged, and the future of the deceased depends on that person's deeds already achieved on earth (Smith, 1998). Such variety in experiences of grief means that there is no single, all-encompassing model of grief nor a single way to grieve (Howarth, 2011). Because of this diversity, no attempt is made here to align to a single model but rather an openness is adopted to allow for individual perspectives to emerge from participants' accounts.

Studies exploring and enhancing our understanding of grief are relevant to Counselling Psychology, as therapeutically we work with bereaved people, and the permanent loss of others through death is something we shall all have to face. Co-twin loss is an important area of study and relevant to Counselling Psychology, as the chances of coming into contact with twins is increasing (Withrow & Schwiebert, 2005), for reasons that will be outlined later. Therefore, healthcare professionals need to understand the unique experience of co-twin loss (Woodward, 1988) in order to help others cope (Withrow & Schwiebert, 2005) and to devise interventions for this specific client group. The existing literature documents that co-twin loss is experienced as more intense than other kinds of losses and is a unique type of loss, but there have not been any more extensive explorations of how this loss is experienced, nor of exactly in which ways it differs from other forms of loss.

Similarly to the explanations of grief proposed by Charmaz and Milligan (2006), in this thesis grief is referred to throughout as an individual's personal feelings and physical responses in reaction to a loss, where loss is referring to death.

Given the possibility of different experiences of loss, a hermeneutic-phenomenological approach to exploring the lived experience of co-twin loss in older adulthood was taken for this study. This position was adopted as a reflection of my position as a Counselling Psychologist in both my research and my clinical approaches. The ethos allows for a focus on individuals' subjective experiences in the context of their personal and social worlds (Smith & Osborn, 2006), and allows access to the meanings they assign to these (Larkin, Watts & Clifton, 2006).

Chapter One: Literature Review

1.1 Introduction

This critical review of the existing literature relating to co-twin loss begins by exploring different perspectives on bereavement. Following this, sibling relationships are briefly explored and then twin relationships are focussed on, in which closeness among twins is highlighted. The concept of identity is also introduced and considered in relation to the formation of identity in twins and how identity is affected by bereavement. Studies exploring older-adult twin relationships are also considered and illustrate the importance of older-adult sibling relationships, both generally, and specifically between co-twins. Studies examining co-twin loss are then reviewed. Gaps in the literature are explored and the proposal for the current study put forward. Within this review, relevance to Counselling Psychology is also documented and reflections on the choice of topic area under study are also made.

1.2 Perspectives on Bereavement

1.2.1 General Bereavement Theories

Stroebe, Stroebe and Hanson (1993) documented that there are two different types of general bereavement theory: depression models of grief and stress models. Stroebe and Stroebe (1987) noted that common responses to death include anger, guilt, regret, anxiety and fearfulness, relief and loneliness. Furthermore, the way we perceive ourselves and the world is modified and identity changes with loss (Stroebe & Stroebe, 1987). Parkes and Weiss (1983) have observed that with spousal loss, the perception of being part of a couple has to change. It has been argued that with the intense closeness that can exist between twins, especially monozygotic (MZ) twins (Segal et al., 1995), both the change in perception of the world and of identity

described above occur, but often this experience of loss is greater than for spousal loss (Bryan, 1995). This could be explained by the idea that twins have never known what it is like not to be a twin, whereas spouses have had their own, singleton identity prior to marriage and can regain the identity of belonging to a couple by remarriage (Woodward, 1998).

1.2.2 Historical Perspectives on Bereavement

In the twentieth century the dominant grief responses of distress were viewed as pathological. Freud (1917) proposed the idea of grief work, where mourning allows for detachment from the deceased. In the latter half of the twentieth century stage-based models emerged: finality and resolution were also seen in these, such as in the five-stage model of loss which was adapted for those grieving (Kübler-Ross & Kessler, 2005). The work of Bowlby and Parkes (1970) on attachment and loss was used to expand this. They developed a four-stage model of grief (Bowlby & Parkes, 1970). In their model, the final stage included letting go of the attachment to the deceased (Bowlby & Parkes, 1970). Problems that emerge with stage models of grief can include failure to encapsulate the complexities of human grief, its uniqueness and diversity. Such models can also promote a pathologising view of grief. They generalise human experience (Rutter, 1983).

1.2.3 Recent Perspectives

More recently there has been a shift of approach from pathologising bereavement, as outlined above, to concentrating on adapting to loss (Davies, 2004). In response to growing dissatisfaction with pathological models (Neimeyer, 1999), there has also been a move towards focussing on meaning-making and lived experiences of loss

(Davies, 2004). Stroebe and Schut (1999) proposed the Dual Process Model of coping with bereavement, where responding to loss involves oscillation between loss-oriented and restoration-oriented coping, for which one engages in non-grief work, for example doing new things and being distracted from grief where earlier models had stressed a focus on the loss.

Other changes in approach have included a shift in emphasis from detaching from the deceased and breaking ties with them (Freud, 1917) to maintaining bonds, an approach in which the adaptive function of retaining these bonds is considered (Klass, Silverman & Nickman, 1996). Contemporary theorists have documented that a constructive reorganisation of the bond with the deceased can be achieved by internalising the deceased as an extension of the self and therefore maintaining psychological proximity to the dead person (Field, Gao & Paderna, 2005). This can be seen as a way of regulating affect, for example by feeling comforted by a sense of the deceased's presence during stressful times (Field, Gao & Paderna, 2005). Gillies and Neimeyer (2006) argued that the existence of continuing bonds can help the bereaved reorganise his or her identity as a survivor. However a review of the literature on continuing and relinquishing bonds shows that Stroebe and Schut (2005) found it was inconclusive whether breaking or continuing bonds with the deceased helped with processing grief. They argue that research needs to accommodate what works across the range of bereaved people's different experiences of grief. To take this on board, it is important to consider research questions that explore the complexities of different relational dynamics in the experience of loss, a discussion of which follows.

1.3 Relationships

1.3.1 Sibling Relationships

Relationships between siblings in childhood can be important for development (Dunn, 1983): siblings can often be sources of emotional support and companionship; older siblings can act as role-models; and sibling relationships can help children obtain cognitive and social skills (Furman & Buhrmester, 1985). The behaviour of each sibling can also create a different environment for the others, showing the direct influence they can have on one another (Dunn, 1983). Sibling rivalry has been noted by clinicians to have a great effect on personality, and birth order, gender and age all affect sibling interests, thinking styles, achievements, conformity and self-esteem in adulthood (Dunn, 1983). This may suggest that with the loss of a sibling, acquired developmental factors could be affected, for example if one sibling had helped instil confidence in another, the death could result in the surviving sibling losing some of this confidence. However co-twin sibling relationships differ from other sibling relationships in the sense that twins have a sibling of the same age (Preedy, 1999) and with the same developmental needs, growing alongside them (Mogford-Bevan, 1999).

1.3.2 Twins

MZ twins are produced when a zygote (fertilised egg) splits into two, resulting in two genetically identical children, meaning that they share 100% of their genes (Bryan, 1983). Dizygotic (DZ), also named fraternal or non-identical twins, occur when two eggs are fertilised by two individual sperm (Withrow & Schwiebert, 2005). The resulting children are genetically like singleton children as they share approximately 50% of their genes (Segal & Ream, 1998). DZ twins seem to run in families (Bryan, 1983) along the mother's familial line (Raffel, n.d.), but the systems behind the

creation of MZ twins and why the egg splits remain unexplained and appear to occur randomly (Bryan, 1983). It has been well-documented that the rates of MZ twin births are similar throughout the globe: three to four in every 1000 births; however rates of DZ twins differ regionally (Bryan, 1983). The lowest rates of DZ twins are found in Japan and the highest rates occur in Nigeria (Bryan, 1983). In the UK in 2012, 11,228 of 729,674 live births resulted in twins (Office for National Statistics, 2013).

1.3.3 Twin Relationships

Some research has documented close and cooperative relationships between twins, which are greater for MZ than DZ twins (Segal & Hersherberger, 1999). Segal and Hersherberger (1999) also found that social closeness was greater for older twins, which could indicate that co-twin loss may have a bigger impact in later life. However this research rated social closeness on a seven-point scale, a rating that for some twins in the study was completed by their parents, so the experience of the twins themselves might not have been accurately reflected. Segal and Hersherberger (1999) acknowledged this but also noted that although the ratings of social closeness from twins themselves and from the parents were not directly comparable, differences were not found in the variances and means in the correlations.

It has been argued that twin relationships can also be experienced as intense, so much so that there have been instances documented, particularly in the psychoanalytic literature, of desires for or fantasies of killing the other (Lassers & Nordan, 1978). Some researchers have recorded adult twin relationships as often so intimate and intense that survivors of co-twin bereavement frequently experience ‘twin yearning’ and try to reinstate the twinship (Sheerin, 1991, p.16) through relationships with

others so that they have a 'surrogate twin' (Hayton, 2009, p.151). Orr (1941) noted that these attempts to find a surrogate twin can occur not just when the true twin is physically dead but also when the twin is away or in new situations, indicating the existence of a strong attachment or bond. Although little research has been carried out in this area, it could be suggested that the twin bond differs in its intensity and dynamics from other sibling relationships.

1.3.4 The Twin Bond

Sometimes twins can become attachment figures for each other, resulting in a co-dependent relationship (Schave & Ciriello, 1983). This means separation-individuation (Mahler, Pine & Bergman, 1975) has to occur from the co-twin, rather than just from primary care-givers (Akerman & Suurveen, 2003). Akerman and Suurveen (2003) found independence was fostered when twins could free themselves from their attachments both to the primary care-giver and the co-twin. However it was noted that this may be more difficult for MZ twins, who were found to be more dependent on their co-twins (Akerman & Suurveen, 2003). Therefore in co-twin loss MZ twins may struggle more as they seem to rely on their co-twins to a greater degree; indeed excessive reliance on a co-twin can lead to a failure to achieve a separate sense of identity (Akerman & Suurveen, 2003).

1.4 Bereavement and Identity

It has been well documented that bereavement affects identity in many different relationship groups, for example spousal (e.g. DeGarmo & Kitson, 1996), parent-child (e.g. Rando, 1991) and sibling (e.g. Balk, 1990). Gillies and Neimeyer's (2006) model of meaning reconstruction states that three meaning-making activities can help

bereaved people create post-loss meanings. One of these is identity change, meaning that the self is reconstructed in response to the loss (Gillies & Neimeyer, 2006).

Research has documented that identity change in sibling relationships can be seen in both negative and positive ways (Oltjenbruns, 1999). Although sibling loss and identity change within this has been studied, Moss and Moss (1989) observed that elderly sibling relationships and the loss of an elderly sibling have been given little research attention. They noted that elderly sibling loss can affect identity and was described by some of their participants as a ‘depletion of the self’ (Moss & Moss, 1989, p.103), but in their study most participants indicated adjusting well to the loss. The loss of a co-twin in older adulthood, however, and its impact on identity, do not seem to have been studied. It may be reasonable to suggest that if the co-twin sibling relationship is different and there is a stronger sense of attachment within it, the experience of co-twin loss may also differ from that of the loss of a non-twin sibling.

1.4.1 Identity, Bereavement and the Twin Bond

The term ‘identity’ is a complex one that reflects ‘diverse theoretical conceptualisations and is an essentially contested concept’ (Mathieson & Stam, 1995, p.287). This research takes the view that ‘identity’, ‘self’ and ‘self-concept’ all represent parts of the process of developing a sense of who one is (Schwartz, Forthun, Ravert, Zamboanga, Rodriguez, Umaña-Taylor & Hudson, 2010), and that the way we see ourselves influences our thoughts, feelings and behaviour (Van Knippenberg, Van Knippenberg, De Cremer & Hogg, 2004).

Since identity has been conceptualised in many different ways (Mathieson & Stam, 1995), there have been extensive debates over whether identity is stable or fluid. For example, Erikson (1968) believed that identity is fixed and stable over time and culture and depends on developmental stages. Gergen and Gergen (1988) rejected this view and described identity as a product of a person's life story. These ideas suggest that the formation of identity is a process that occurs through multiple experiences depending on context: identity is context specific and individual identity fluid and re-narrated, an ongoing discovery of new meanings and a changing sense of self (Brennan, 2001). On this basis, it could be argued that identity is formed through and by lived experience, and is constructed and fluid rather than fixed (Brennan, 2001).

In relation to this, Identity Process Theory (Breakwell, 1986) posited fluidity and that processes of assimilation and accommodation affect identity structure (Breakwell, 2010). Assimilation is where new components are absorbed into identity and accommodation is where the existing structure of identity adapts, to make way for these new components (Breakwell, 2010). Breakwell (2015) also documented ideas about threats to identity, many occurring with different types of losses in old age. Bereavement is one kind of loss that can be considered to pose some threat to identity (Moss & Moss, 1989). Bury (1982) also stated that profound life changes can threaten one's identity and sense of self and again bereavement could be argued to count as one such change (Shuchter & Zisook, 1993). Because siblings are often central to one's identity development (Moss & Moss, 1989), it would be unsurprising for the loss of a sibling to impact one's sense of identity.

There has been some research to suggest that co-twin siblings' experience of identity varies. Leonard (1961) noted that the degree to which twins resemble each other, affects the intensity of identification with one another and how the self is seen. Furthermore, Schave and Ciriello (1983) found that the identity formation of twins is affected by the co-twin's presence, so that many define themselves in relation to the other (Tancredy & Fraley, 2006). In identification with one's twin, a 'twinning reaction' arises which is 'a fusion between self and twin' (Siemon, 1980, p.389). This arises from different sources, including physical similarities and reactions from other people (Siemon, 1980).

Siemon (1980) observed that this paired identity does not cause psychological threat if the unit can function, but that problems arise when separation occurs, as then the fragility of the sense of self manifests as the felt loss of a part of the self. In this way survivors of co-twin loss may lose a means of identifying themselves (Macdonald, 2002), often expressed in lay terms as a feeling of existing as 'just half' (Hayton, 2009, p.149). It has also been argued that surviving twins take on qualities of the deceased co-twin, feeling that they must assume some of these characteristics or else exist as half a person (Bryan, 1995). On the basis of this research, it could be suggested that the way twins see themselves changes with the loss, as a result of an entwined identity and attachment to the co-twin in life. It could further be argued that if the attachment remains throughout the life-course, and if separation-individuation (Mahler, Pine & Bergman, 1975) between the twins does not occur, the experience for a twin of co-twin loss in later life may have a different impact from that in other sibling relationships.

1.5 Older Adult Twin Relationships

Sibling relationships, both twin and non-twin, tend to be significant throughout the lifespan (Cicirelli, 2010). They are likely to be sustained into old age, as they are often the longest relationships one has (Neyer, 2002). In Cicirelli's (1995) study, for example, it emerged that in America nearly 78% of people over sixty years old were still in contact with at least one of their siblings and that emotional closeness increased as they got older. The typical sibling relationship appears to follow a U-shaped curve over the life-course, by which during adolescence and early adulthood, siblings withdraw from one another and become more concerned with other matters of life such as mating, building their own families, or developing their careers (Neyer, 2002); after this period, siblings draw closer together again, when children are leaving home or the siblings themselves are reaching retirement, a time when the sibling bond may strengthen and intensify and siblings become sources of support for one another.

Neyer (2002) examined this process for MZ and DZ twins and found that, although for each group of twins this U-shaped curve existed, it was slightly different for each of the two groups. For MZ twins the U-shape of support and bond strength increased again at an earlier stage and increased considerably after children left home or the twins were reaching retirement (Neyer 2002). Neyer (2002) also found that over the whole adult life-course, MZ twins were in contact more often, lived closer to each other, provided more emotional support to one another and felt emotionally closer than DZ twins, suggesting that loss of an MZ co-twin could be more extreme. The quality of DZ twins' relationship was highly dependent on frequency of contact, whereas this factor had less impact on the quality of relationship for MZ twins (Neyer, 2002).

In relation to this, Pietila, Björklund and Bülow (2012) also found that, among those with an age range of 70-91, twins were closer emotionally to each other than non-twin siblings. If a closer twin bond appears both for MZ twins and for older twin relationships of either sort, it could be argued that co-twin loss for these groups may be a more extreme loss experience than other kinds of losses.

1.6 Existing Literature on Co-twin Loss

Twins seem to be the so-called ‘forgotten mourners’ in that they are under-researched (Kemp, 1999, p.22). As discussed, their bond is different as it begins from conception, so they experience a type of loss when their co-twin dies that others cannot experience (Withrow & Schwiebert, 2005). The surviving twin is of the same age and sometimes the same gender, and may share more genes with the co-twin than with other siblings; in these ways twins have what has been described as ‘higher access’ to each other (Watzlawik & Clodius, 2011, p.43). They can be affected deeply (Withrow & Schwiebert, 2005), being more likely to experience a loss of a part of themselves and to depend on one another (Morgan, 2012).

There have only been a few co-twin death studies. These studies have taken a positivist perspective, using quantitative enquiry. For example Segal (2009) looked at suicidal behaviours in twins whose co-twins had committed suicide, finding that MZ twins attempted suicide more often than DZ twins. This may suggest that there is a closer bond between MZ twins, although as grief was more intense for those whose co-twins had committed suicide (Segal, 2009), it could be argued that cause of death is also a factor, as indeed Bailey, Kral and Dunham (1999) suggested.

Another study conducted by Segal, Wilson, Bouchard and Gitlin (1995) examined grief responses to co-twin loss in MZ and DZ twins using the Grief Experience Inventory (GEI). They found higher GEI scores for MZ than DZ twins and MZ twins felt more guilt about a co-twin's death, which could arise from MZ twins assessing themselves to be closer to each other (Segal et al., 1995). However, the study has questionable reliability, as internal consistency across the different subscales including the GEI varied. The measurement used for reliability is Cronbach's Alpha, with a general requirement that scores should be 0.8 or above to be considered reliable (Bryman & Hardy, 2009), but the Cronbach's Alpha scores for the scales used in the study by Segal et al. (1995) ranged from just 0.52 to 0.84.

A further study by Segal and Ream (1998) looked at grief intensity in co-twin loss compared to loss of a non-twin relative. They used the Grief Intensity Scale (GIS) and found grief was more intense for co-twins, and especially for same-sex twins, and that MZ twins took longer to get through their grief than DZ twins (Segal & Ream, 1998). This concurs with Woodward's (1988) findings, although potential problems with the GIS include its adaptation from a measure used by Littlefield and Rushton (1986), who had already adapted it; there is no information about how it was modified and what the scale's validity and reliability was. Claiming grief intensity can be measured by a seven-point scale is in itself questionable, as grief is a complex emotion to conceptualise and measure (Stroebe et al., 2003).

Segal and Ream (1998) also found that grief was less intense for a loss that had occurred at a younger age, or for younger participants in the study, and that the greater the period of time between the loss of the co-twin and the present day, the less

intense the grief. However the above findings are partly contrary to Hayton's (2009) and Woodward's (1988) work, which states that loss of a co-twin at a younger age is more devastating as the survivor has to face the world alone.

The research discussed above, although interesting, due to design issues needs to be treated with caution. Both the studies by Segal and Ream (1998) and Segal et al. (1995) recruited participants through various sources, for example support groups and the media. This could produce biases in the data through the possibility that some participants may have invested more in the loss than others (Stroebe et al., 2003), for example those who were attending support groups who constituted almost half of the sample of Segal et al. (1995). Both studies also used the Nichols and Bilbro (1966) physical resemblance questionnaire to determine zygosity. This measure has a 90% accuracy rate and correlates highly with serological testing (93%) (Munn, Stallings, Rhee, Sobik, Corley, Rhea & Hewitt, 2010), but this was modified for use with single twins. In this context it was an unreliable way to determine zygosity, as twins can sometimes appear non-identical when they are in fact identical (Segal, 1997).

Furthermore, Segal and Ream's (1998) sample consisted of ranges that were too wide to give reliable results. Participants' ages when participating in the study were 16-84 years old, ages at loss were 15-79.5, and years since loss were 0-45. This could render the data meaningless as such broad ranges are likely to be reflected in a broad range of grief responses. Elderly people, for example, may have more experience of loss and have developed more ways to cope; someone who has experienced a loss for longer may have developed more acceptance of the death and so be experiencing less grief. While this is actually one of the hypotheses of Segal and Ream's (1998) study, to be

tested more validly the ages and years would need to be more tightly controlled. The impact of losing a co-twin may differ as a function of age, as past bereavement research suggests (Anderson & Taylor, 2006).

A further point to consider, is that the results in the studies by Segal and Ream (1999) and Segal et al. (1995) included the use of correlations. Correlation does not indicate causation, but rather that relationships exist between variables (Field, 2000).

1.7 General Critique of Co-twin Loss Studies

Although many of the above studies may be flawed, grief is a difficult topic to research because of its sensitivity (Nadeau, 2008). In addition to design issues, problems arise in quantifying the concept of grief, and questions arise about how grief is conceptualised, normalised and pathologised, especially as grief has no universal meaning but has different cultural interpretations (Rosenblatt, 1993).

The study by Segal et al. (1995), for example, does not make clear exactly what was being measured. There are differences between grief and guilt. As already discussed, grief is the emotional response to a loss and is a complex emotion that is a variation of the emotion of sadness (Charmaz & Milligan, 2006). Guilt, however, is an emotion that arises when a person feels they have failed to comply with a moral standard that they consider important (McNally, 1993). A person's reaction to someone's death could include feeling responsible, or feeling guilt for not having done more for the deceased (Kübler-Ross, 1970), or guilt about feeling relieved that the person is dead, for example if that person had suffered a long illness (Elison & McGonigle, 2004). Another kind of guilt is termed 'survivor guilt', and arises from having lived when

other people rated as equally or more worthy of survival, have died (Piorkowski, 1983). Common also is a feeling, within survivor guilt, that the deceased's death in itself was a factor enabling the survivor to remain alive (Piorkowski, 1983). A closer look at the study by Segal et al. (1995) reveals that the subscales of the GEI included measuring despair, anger/hostility, guilt, social isolation, loss of control, rumination, depersonalisation, somatisation and death anxiety; in looking at grief, the researchers have termed it so as to encompass all these areas, including guilt, but the GEI is also reported as not including crying or being sad, which are often thought of as common, general grief reactions (Tomita & Kitamura, 2002), albeit culturally variable behaviour (Rosenblatt, 2008). Stroebe, Stroebe and Schut (2003) noted that even measures of grief that are standardized have limitations, for example because some topics are not included in the measures.

Problems with the conceptualisation of grief are also seen in Segal's (2009) study: she proposed that participants might have characterised their grief as suicidal ideation even if suicidal thoughts were not really present, and she concluded that their consideration of suicide needed to be studied further. Her observations arose because the broad term 'suicide' had been used without reference to wanting to die, suggesting that participants may have interpreted the meaning of suicide differently. Given the above, it can be argued that many of the quantitative studies, although interesting and useful, may not fully encapsulate the individuals' lived experience of loss.

1.8 Rationale for Qualitative Research into Co-twin Loss

Macdonald's (2002) work was the only accessible study found that directly researched twins qualitatively. Macdonald's (2002) primary focus was the experience

of twinship, and she described how MZ twins are often viewed as a unit so that when one is lost, the other can feel no longer whole. Hoffman (1991) argued that because MZ twins look the same physically, they are treated and behave similarly, and this can lead to their feeling joined as one (Siemon, 1980). MZ twins can experience less loneliness, and for some loneliness is unimaginable (Macdonald, 2002), so when it occurs through co-twin loss, it is particularly hard to deal with. Potential problems arise with some of Macdonald's (2002) recruitment procedures: she recruited some participants from The Lone Twin Network, a charity involved in supporting bereaved twins. This may have biased the sample, as participants from support groups may be more involved in their grief and it may form a more central part of their lives than for other participants, or they may use their involvement in the research process as a way of trying to come to terms with their loss (Stroebe et al., 2003).

From her research, Macdonald (2002) concluded that qualitative studies using open-ended interviews and involving more males would be useful, and that little work had been done on the effects of co-twin death in later life. Moss and Moss (1989) noted that sibling loss for the elderly has been almost ignored.

Previous research reveals in different ways that a strong bond exists between co-twins, particularly MZ twins (Segal et al., 1995), and that this bond is generally viewed positively by the twins themselves (Prainsack & Spector, 2006). Moreover the quality and strength of the bond between twins seems to be greater than that between non-twin siblings (Neyer, 2002), with the MZ twin bond being generally stronger than the DZ twin bond (Neyer, 2002; Segal & Ream, 1998; Segal et al., 1995). Some literature offers examples of twins feeling each other's pain, or even their death, when

miles apart, however this material is anecdotal and is often dismissed by those seeking evidence of the nature of the bond between twins (Playfair, 1999).

Although there is some research on the struggles of being a twin, it tends to look at feelings of ambivalence (e.g. Sheerin, 1991; Von Broembsen, 1988). It could be true that survivors experience intense loss that singletons may not understand (Withrow & Schwiebert, 2005), and more research needs to be carried out in this area, especially with older adults who seem to be an under-researched population with regards to their sibling relationships and sibling loss (Moss & Moss, 1989).

Some impacts of co-twin death have been suggested or documented but not actually studied, such as the suggestion that twins may find constant reminders of the deceased in themselves and feel guilty about living and surviving (Bryan, 1995).

Some survivors feel anger for a number of reasons including; anger with the deceased for leaving them alone in the world and prompting guilt for having caused unhappiness in the family, and anger with ‘their parents for “allowing” the twin to die’ (Bryan, 1995, p.191). Sometimes, however, twins feel a sense of relief; ‘We were both a burden to each other’ (Wallace, 1993, p.237). This ambivalence is also seen in Sheerin’s (1991, p.13) work: ‘being an identical twin is both tormenting and gratifying’. The variance that is present in these ideas suggests that phenomenological studies that capture rich, in-depth information (Malim, Birch & Wadeley, 1992) would be useful in order for us to better understand the impacts of co-twin loss.

The aforementioned studies on co-twin loss seem to be designed from a positivist perspective, which has certain limitations. Positivism posits that language directly reflects external reality (Ponterotto, 2005), a position vulnerable to the fact that people can describe things in different ways, raising the possibility that there might not be the single, objective, external reality that positivism postulates. Racher and Robinson (2002) have argued that objective and subjective reality are not mutually exclusive, that there is no absolute source of knowledge, and that findings cannot be proven. One difficulty with a positivist approach for this sort of research is that positivism advocates for complete removal of the researcher, but because enquiry is not value-free (Racher and Robinson, 2002), this absence can never be entirely achieved. Other problems include a lack of recognition of factors such as a person's culture, society and the time period in which they live, nor of how these factors contribute to shaping knowledge (Willig, 2013).

The quantitative co-twin loss studies note MZ co-twin loss as worse than other kinds of losses, but do not enlighten us about how the loss experience feels for the co-twin, or how it is experienced as worse, or how it differs from, other kinds of loss.

Qualitative studies could help address this better by focussing more on offering richer, 'descriptive accounts of the phenomena under investigation' (Smith, 2008, p.1). Due to problems in quantifying grief and capturing it on a scale, it could be argued that there is a case for phenomenological research looking at loss experiences. This way of studying grief instead helps to illustrate the essence of the experience through the meanings participants ascribe to it (Creswell, 1998). Phenomenological approaches also do not 'impose order' on participants but allow them to freely describe their

experiences (Soricelli & Utech, 1985, p.178), a method that is ideal for the study of a sensitive topic such as grief (Nadeau, 2008).

Quantitative studies such as those of Segal et al. (1995), which looked at grief responses such as guilt levels, and Segal and Ream (1998) and Woodward (1988), both of which looked at grief intensity, capture different aspects and levels of grief, but there is no universal agreement on the definition and measures of grief (Howarth, 2011). For example, as previously seen, the scales used by Segal et al. (1995) did not include items about sadness or crying, which are often considered common responses to grief (Tomita & Kitamura, 2002). This also raises questions about cross-cultural and religious differences in grieving: in Islam, for example, grieving is only permitted for three days (Venhorst, 2013). Such drawbacks in the quantitative studies provide a case for qualitative and phenomenological enquiry into grief, as this kind of enquiry is able to capture more detail and allows for freedom in the expression of experience (Soricelli & Utech, 1985).

The case for the new approach to the subject represented by this thesis is strengthened by conclusions in existing studies on co-twin loss that more research is needed on the topic area (Withrow & Schwiebert, 2005), that siblings' relationships in older adulthood are under-researched (Moss & Moss, 1989), and that existing studies have not looked at the phenomenon of co-twin loss in older-adults.

1.9 Relevance of Co-Twin Loss to Counselling Psychology

This thesis is particularly relevant to Counselling Psychology as it has a Humanistic values base (Strawbridge & Woolfe, 2010) and, within Humanistic theory, the self is a

prominent and important concept (Rogers, 1961): it explores the way people see and define themselves (Douglas, Strawbridge, Kasket & Galbraith, 2016). Past twin research has shown that twins often see themselves as a unit (Macdonald, 2002) and this is reinforced by other people (Piontelli, 2004), as when they are referred to by others as 'the twins'. This joined sense of being can lead to psychological maladjustment, for example survivors feeling incomplete when a co-twin dies (Withrow & Schwiebert, 2005), and distress being felt as identity needs to shift (Stewart, 2000). This brings us back to the relevance of a phenomenological perspective, as it and Counselling Psychology both concentrate on individual perspectives and understanding experiences (Strawbridge & Woolfe, 2010), and on the context of people's social worlds (Smith & Osborn, 2006).

Exploring co-twin loss has another important benefit for Counselling Psychology: the chance of Counselling Psychologists coming into contact with twins is increasing as women are waiting longer to have children (Withrow & Schwiebert, 2005). Ovulation becomes more irregular with age, increasing the chances of conceiving multiples, and infertility treatments increase those changes yet further (Withrow & Schwiebert, 2005). Correspondingly, the chances of Counsellors coming into contact with bereaved twins are also likely to increase (Withrow & Schwiebert, 2005). The formation of support groups for twinless twins over the last fifteen years has further demonstrated a growing need to address this kind of loss (Segal et al., 1995).

Healthcare professionals need to understand the unique experience of loss that twins go through (Woodward, 1988), in order to help them cope (Withrow & Schwiebert, 2005). By gaining an insight into survivors' experiences through hearing them

described first-hand, Counselling Psychologists can then begin to really understand and empathise with these clients, and insight may also help them carefully devise their interventions for this specific client group.

Furthermore, if therapists are able to have an understanding of the common issues that twinless twins face, healthcare professionals can then also help the bereaved families of twins to understand what the survivor is also uniquely going through (Pector, 2002).

1.10 Reflexivity

The motivations behind research are important to consider as these will affect the whole of the research process including the nature of the data gathered and how it is analysed, as these are ‘grounded in subjectivity’ (Morrow, 2005, p.254). One angle of motivation to consider is why the particular topic area was chosen and this has been reflected on at length, concluding a number of ideas.

Firstly, loss could have been conceptualised in a number of ways, not only relating to bereavement. For example, I could have chosen to explore loss in terms of temporary separation, such as a geographical separation if a co-twin moved abroad, rather than loss through death and thus a permanent, finite and irreversible type of loss. I have reflected on why this might be and I have considered that perhaps this relates to some level of death anxiety (Stern, 1968) that I hold, and the research as a process and subconscious desire to search for some answers in relation to coping, as bereavement is something most of us will have to face in our lives.

Throughout my personal therapy, themes around attachment and different forms of loss have permeated the sessions and continue to do so, highlighting the importance of the concepts and my experiences of them. This bridges my personal experiences, personal therapy and clinical work as relational factors such as the therapeutic relationship are argued to be central in the work of therapy in the common factors approach to therapy (e.g. Messer & Wampold, 2002). This can also be related to the current research as it too has a focus on relationships, both in life and death.

In addition, I have reflected on why I chose to look at co-twin loss rather than, for example, non-twin sibling loss. Being one of five female siblings but not being a twin myself, I held assumptions that co-twin relationships were closer than non-twin sibling relationships and held a stronger bond, perhaps because of growing alongside someone of the same age at the same time and with a very similar physical resemblance. I imagined this would affect sense of self and that this could therefore have a greater impact on the loss experience.

1.11 Conclusion

This literature review has shown that there is a paucity of qualitative research on co-twin loss, and the proposed study attempts to begin addressing this gap. The way grief and bereavement is looked at and thought about has changed over time, and they may manifest in different ways in different relationships. Sibling and co-twin sibling relationships differ, and existing literature suggests that the nature of the twin bond is unique and that identity is affected by the presence of the co-twin, most apparently when twins feel they have a shared identity and a lack of a separate sense of self.

Therefore when loss occurs and is permanent through death, it can affect the way twins see themselves and how they cope.

A review of the existing literature on co-twin loss suggests that it is a unique type of loss and is experienced as different from and worse than other kinds of losses. This is attributed to a number of factors including the attachment and bond between twins, which is seen as unique, and also to genetic relatedness. However as the existing studies are quantitative in nature, it is unknown in which ways the co-twin's loss is different or worse, and what the actual experience of the loss is like for the remaining twin. Qualitative studies will complement these and broaden knowledge of the topic area (Stroebe et al., 2003). The centrality of meaning-making in coping with grief has been highlighted more recently (Davies, 2004), and how people make sense of their experiences and the meaning they assign to them is captured better by qualitative than by quantitative research methods. IPA is one methodology that allows for this, as it focuses on how people make sense of their subjective experience (Smith et al, 2009). For this reason an IPA study is proposed here, which aims to explore the research question 'What is the experience of the loss of an identical co-twin in older adulthood like for the surviving identical twin?'.

Chapter Two: Methodology

2.1 Overview

The overall aim of this study is to explore the experience of the loss of an identical co-twin in older adulthood. This chapter includes the rationale for adopting a research paradigm of hermeneutic-phenomenology and the methodology of IPA. Quality assessment criteria and ethical issues are also considered. The research design framework details participant recruitment and the sample, measures, data collection and analysis. To demonstrate transparency and cohesiveness (Yardley, 2008), reflexivity is also documented in grey font.

2.2 Research Paradigm

Phenomenology focuses on experiences of everyday life and what is happening in the moment, and these have been incorporated into many counselling approaches, particularly those that focus on the here-and-now (McLeod, 2011). A phenomenological stance forms the basis of Counselling Psychology in particular because of the humanistic values that are fundamental to Counselling Psychology and its practice (Douglas et al., 2016). The phenomenological stance recognises that meaning is central to our lives and our relationships with ourselves, others and the world (Douglas et al., 2016). In this way it is a Humanistic-Phenomenological paradigm that underpins Counselling Psychology (Woolfe, 1990).

Hermeneutic-phenomenology (Heidegger, 1962) was the chosen research paradigm for this study, and it takes the view that our experiences are the product of interpretation (Willig, 2013). It is a paradigm that sits between relativism and realism (Willig, 2013), phenomenology being a philosophical approach that focuses on the

study of lived experience (Smith et al., 2009) and the ways in which things emerge into our awareness (Langdridge, 2007). Heidegger's phenomenology views the 'person-in-context' and places an emphasis on interpretation (Smith et al., 2009, p.17). Phenomenology therefore links with hermeneutics, as phenomenology is involved with the examination of meaning whose appearance can be hidden (Creswell, 2009). Hermeneutic-phenomenology is associated with Heidegger and emphasises that interpretation originates from the phenomenon itself and close attention that is paid to it, rather than from elsewhere (Eatough & Smith, 2008). The chosen paradigm is related to this research aim of exploring the experience of co-twin loss in older adulthood, in that both the paradigm and the research aim focus on lived experience, subjectivity of experience and the person in context (Smith et al., 2009).

IPA was deemed the most appropriate methodology to employ as it is compatible with the philosophy of Counselling Psychology. Ponterotto, Kuriakose and Granovskaya (2008) acknowledged that psychotherapists and counsellors are naturally drawn to qualitative inquiry due to its varied methods and emphasis on people's emotive and cognitive experiences from their socially-constructed worldview. IPA is also appropriate in its philosophical underpinnings involving phenomenology, hermeneutics and idiography (Smith et al., 2009). These also sit well with the researcher's personal epistemological position. IPA was developed in the 1990's (Smith, 2004) as it was felt that subjective experience had been neglected and there was a need to establish 'a qualitative approach to psychology, grounded in psychology' (Eatough & Smith, 2008, p.180). Its objective is to look at subjective experience and how people make sense of their personal and social worlds (Smith & Osborn, 2008) and it addresses the uniqueness and wholeness of people, giving an in-

depth picture (Malim et al., 1992). IPA was chosen because experiences were being accessed (Willig, 2013) and no study to date had looked at co-twin loss in older adulthood through this methodology. IPA has a wide range of theoretical influences and states no distinct epistemological standpoint (Smith, 2004), but phenomenology is a major theoretical underpinning of IPA (Smith et al., 2009). Key figures in phenomenology include Husserl, who emphasised that conscious awareness is key to our build-up of knowledge and the reality we perceive (Langdridge, 2007); Heidegger, who emphasised interpretation; Merleau-Ponty, who discussed the body being located in lived experience, since we engage with the world through our bodies; and Sartre, who focussed on existential phenomenology, stressing the developmental nature of human experience (Smith et al., 2009). IPA recognises that researchers cannot directly access people's experiences but can attempt to get close to them, as the meanings people assign to experiences could be argued to represent the actual experience itself (Eatough & Smith, 2008), thus connecting it to the hermeneutic tradition (Smith, 2004).

The second major underpinning of IPA is hermeneutics; the theory of interpretation and it focusses on the idea that our 'fore-conceptions' are involved in a cyclical process in interpretation because they exist prior to interpretation (Smith et al., 2009, p.25). However it may be that only through interpretation do we understand which parts of these fore-conceptions are relevant, creating an iterative process in the analysis (Smith et al., 2009). Idiography is also involved in IPA, as each case is studied in detail in its own right (Shinebourne, 2011). IPA is committed to an emphasis on the specifics: the analysis is deep and focuses on particular people in specific contexts (Harper & Thompson, 2011).

A case can be made for IPA to be used in studies focusing on loss and bereavement, following Smith's declaration (2011, p.14) that lived experience is central to IPA and that it is 'primarily concerned with experience which is of some existential import to the participant'. IPA asserts that we can understand experience by examining the meanings attached to experience, which in turn sheds light on existential areas of psychology (Smith et al., 2009). IPA has already been applied to other studies exploring bereavement (e.g. Golsworthy & Coyle, 2001), as bereavement is a sensitive topic area. Nadeau (2008) proposed that phenomenological approaches seem to be the most appropriate for studies looking at bereavement, and IPA, as one such approach, is an appropriate method for the current study's exploration of the loss.

Several options could be considered for different ways in which the current study could have been conducted, and these may also therefore be considered for future research. Thematic analysis accounts, for example, are more descriptive, and the approach is nomothetic, focussing on generalisability, but due to a desire to focus more on the individual in a particular context and on more in-depth accounts of experience (Gil-Rodriguez & Hefferon, 2011), it was not chosen over IPA. However, it could have been used to explore patterns within the data (Braun & Clarke, 2006), and may have yielded similar results to those obtained.

Discourse analysis is another option that could be considered. It focuses on social interaction through speech and the text (Potter & Wetherell, 1987), and could have been an interesting method for exploring how people talk about the experience of co-twin bereavement. This may be a possibility for future research, but in this study IPA was preferred as it involves first understanding what the experience is like more

broadly; this could then set the scene for focussing more deeply on language and how people talk about the experience once an understanding of what the experience itself is like has been obtained. Discourse analysis also does not look beyond the data for more information that could help interpret it (Willig, 2013), such as non-verbal signals and the context in which the words are said (Gergen, 1999), while IPA did allow for this and could provide a broader understanding of the loss experience yet at the same time focuses on subjectivity. Discourse analysis ‘does not address questions about subjectivity’ (Willig, 2013, p.124).

Narrative analysis could also have been considered as a method to use. It involves the stories we create and exchange (Murray, 2008). The interest in narrative approaches that are used in grief therapy is growing (Neimeyer, 1999), which could suggest utility in bereavement research too, as narrative grief therapy shows that story-telling in bereavement aids coping as it helps with sense-making (Bosticco & Thompson, 2005). This could help us obtain information about the loss experience within bereavement research. However narrative analysis also includes examining the endpoints of a story, whereas it may be argued there is really no endpoint to bereavement, as its effects may be limitless.

Semi-structured interviews were not the only available method of data collection. Diaries or focus groups could have been used as alternative data collection methods within IPA (Pietkiewicz & Smith, 2014) but the latter pose particular challenges for bereaved people (Briller, Schim, Meert & Thurston, 2007). The potential for harm, for example, is heightened because the topic is sensitive, and because of group dynamics, which can result in people revealing more personal information or more of their

emotions than they had intended (Briller et al., 2007). These points and the preferred method of semi-structured interviews in IPA in general (Pietkiewicz & Smith, 2014) meant that they were opted for in the current study.

2.3 Embedding Quality in the Design

A rapid increase in the use of qualitative methods in psychology has led to debates about quality and validity (Yardley, 2000). As qualitative research methods and epistemologies are so diverse, this has led to a broad variety of procedures and traditions (Barker, Pistrang & Elliot, 2016). While this has provided a complementary set of procedures to the more traditional quantitative approaches, it has simultaneously led to an increased difficulty in illustrating the validity and value of the qualitative methodologies (Yardley, 2000). There has been a desire for set criteria against which qualitative methods can be evaluated, but because of the diversity and variance in these methods' epistemological standpoints, it can be argued that one set of criteria can never cover the extensive basis of them all, and that a set of standards against which to evaluate qualitative methodologies is in fact not compatible with the qualitative research methods themselves (Meyrick, 2006; Yardley, 2000). Despite this, over time suggestions for guidelines for good practice have been developed, which allow qualitative researchers to illustrate the ways in which their studies are reliable and rigorous. Yardley's (2008) and Meyrick's (2006) guidelines are two examples that cover a broad range of qualitative methodologies and were adopted in this study.

Sensitivity to context (Yardley, 2008) has been addressed in this thesis by conducting an in-depth review of the existing literature in the topic area, which is found in

chapter one and illustrating the development of and rationale for the research question. Sensitivity to the participant's perspective and their sociocultural context (Yardley, 2008) should also be considered, meaning that one must remain sensitive to the participant and his or her experience as individual and unique. This was addressed through reflexivity and transparency throughout the research process. An attempt has been made to demonstrate transparency and coherence through a clear research question, and a thorough depiction of the research design, method and procedures used, as well as through reflexivity (Yardley, 2008). This includes consideration of the epistemological standpoint adopted, as well as the nature of the author's closeness to the data by admitting and accepting that the researcher's own experiences contribute to shaping the research findings (Meyrick, 2006). This is explored in the discussion chapter. Research quality has also been monitored by making sure that the interpretations made in the analysis are clearly linked to both the text from the interview transcripts and the contexts from which they have been drawn (Willig, 2013). A full paper-trail also supports the whole research process (Smith et al., 2009).

A third recommendation is commitment to rigour (Yardley, 2008), indicating that the analysis involves adequate depth and insight. This has been attempted, although judgement on this ultimately lies with the reader. Sampling is also important for such a commitment to rigour (Meyrick, 2006). It has been illustrated that the sample is partly homogeneous and is purposive and as a result care was taken to try to align the sampling theoretically with the chosen methodology as far as possible. The final guideline is impact and importance (Yardley, 2008), and IPA's idiographic focus helped to communicate how these particular participants made sense of their experiences in the specific context (Smith et al., 2009).

2.4 Ethical Considerations

In the design of the research project and application for ethical approval, The British Psychological Society's Code of Ethics and Conduct (2009), the British Psychological Society's Code of Human Research Ethics (2010) and the University of East London's (UEL) Code of Good Practice in Research were consulted and taken into consideration. Ethical approval from The Research Ethics Committee at UEL was granted on 29th November 2012 and an amendment was also approved on 20th March 2015 (appendix one). While deep-seated emotions may re-emerge during the research, these may be outweighed by the knowledge that understanding gained from the study can be used in order to help survivors cope.

Recruitment from the Department of Twin Research was subject to ethical approval from UEL, and a research proposal was approved by the Department of Twin Research senior management team (appendix two). Lone twins who expressed an interest in participating in the research were sent an information sheet (appendix three) to inform them fully of the aims of the study and what the research would involve. Participants were made aware that talking about the subject-matter might bring up unpleasant emotions, so that they could consider this before deciding whether to participate. Participants were also notified of their right to withdraw at any time without reason and without repercussions. On meeting twins who had expressed a willingness to participate, the researcher again explained the research and interview process and what it involved, and any questions were answered, to ensure that participants understood fully. Consent forms (appendix four) were then signed in order to document informed consent. Obtaining informed consent conveys part of a

dedication to a ‘democratic, non-hierarchical relationship’ with participants, which is also one of the principles of Counselling Psychology itself (Kasket, 2012, p.67).

As it was anticipated that survivors might feel distress from speaking about their experiences, after each interview they were offered contact details of national organisations providing support and counselling for bereaved people, such as Cruse Bereavement Care. They were also provided with details of support available specifically for twins who have lost a co-twin, such as the Twin and Multiple Births Association’s bereavement support group and The Lone Twin Network. Some websites and recommended books on the subject were also included on the debrief sheet (appendix five). Participants were also informed of how they could contact the researcher for up to one month after data collection, if concerns or questions relating to the research arose.

All data was kept confidential and stored securely. Interviews were transferred straight from a dictation machine to a password-protected laptop. Names that appeared in transcripts were replaced with initials before hardcopies were printed and pseudonyms are used throughout this thesis. Any data that might contribute to revealing participants’ identities was also altered or removed. All signed consent forms have been kept securely in a safe, locked place and will be destroyed when the research has been completed and has passed the assessment process.

Even when the listener is not a lone twin, hearing other people’s sufferings could have had an impact on the listener. To deal with any potential emotional distress that may

have arisen, engagement in personal therapy throughout the time the research was conducted and was considered important and something that was adhered to.

2.5 Research Design Framework

2.5.1 Sampling and Recruitment

A purposive sample was employed as aligned with IPA (Smith et al., 2009). It was required that all participants had formerly experienced losing their identical co-twin. Ten participants were recruited. The recommended number for IPA studies ranges from ten (Reid, Flowers & Larkin, 2005) to six (Smith et al., 2009), with a suggestion by Smith (2008) of three for researchers new to IPA. Six was originally chosen as a number felt to be a middle option and appropriate for the level of research, but all those who volunteered were interviewed. This was felt to be useful due to the nature of the topic, which aroused thoughts about its potential to affect interview quality. Equal numbers of male and female participants were aimed to be recruited, as past studies have been female-dominated (Segal et al., 1995; Macdonald, 2002), but the final sample consisted of nine females and one male volunteer. This perhaps reflects a tendency for females to volunteer for research in general more frequently than males, at least for survey-based research (Curtin, Presser & Singer 2000). Findings in previous research have been mixed on whether, as common conception in the Western world has it, women talk more about their emotions than men; if this is true, it could in turn mean that women are more prepared to talk about the difficult emotions and experiences that might be encountered in grief.

Causes of co-twin death were noted but did not form part of the recruitment criteria, as otherwise problems may have arisen in acquiring enough participants (Gibbes,

personal communication, April 7, 2011): advice on carrying out research in this area states ‘it is probably necessary to look beyond the usual factors – age...type and expectedness of loss..’ (Macdonald, 2002, p.224). In addition, because the leading cause of death for both males and females fifty years old and above and including and surpassing eighty years of age in England and Wales in 2014 was illness (Office for National Statistics, 2015a), the causes of death in co-twins of potential participants may have been similar. In the final sample this was true. All participants noted their co-twins cause of death as illness. Circumstances around the illness were noted, as these could have differed, for example between a long-term illness and a sudden life-threatening illness, and therefore could have affected the results. This is discussed in the final chapters of this thesis. In addition, writings concerning the IPA methodology state that while a homogenous sample is desirable, the extent of this varies between studies due to the nature of qualitative research and depending upon the topic area (Smith et al., 2009). The sample for this study was partly homogenous, for example participant zygosity was the same and all twins were raised together, as the presence of the co-twin affects the sense of self (Withrow & Schwiebert, 2005) and life-space shared by twins correlates with the levels of stress experienced from the death (Davies, 1988). In the final sample all co-twin causes of death were expected illness.

Because of the mixed findings on whether or not co-twin loss is worse with age, and the lack of studies on co-twin loss in adulthood, initially loss at eighteen years or above was chosen to be examined as eighteen constitutes adulthood in our society. Also, in adulthood twins tend to be in closer contact than other siblings (Pector, 2002) and it was believed that comprehensive accounts of the experience would be

collected, as these participants would be able to articulate them better with the more developed cognitive ability of adulthood (Moskowitz, Porretta & Silcher, 2005).

The initial intention was to look at co-twin loss in terms of identity, and so sampling of a younger age group of twenty- to thirty-year olds was being considered, as research suggests that identity is formed and consolidated in the period from eighteen to twenty-five years of age, termed 'Emerging Adulthood' (Arnett, 2000, p.469). In addition, although the bulk of identity research has focussed mainly on adolescence, it does show that identity formation is actually rarely achieved towards the end of adolescence (eighteen years old) but that identity development actually continues into a later period (Arnett, 2000).

However the focus of the research changed as it was being designed and as the preliminary stages progressed. It evolved into a project looking at co-twin loss in older adulthood and what the loss experience was like more generally. Older adults were chosen for practical reasons of obtaining participants; because identity is already formed and consolidated by emerging adulthood (Arnett, 2000) and so by old age, the focus of the research had to change. This proved important, as no study to date has looked at co-twin loss in older adulthood and the general population in the UK is now living longer than in the last century (Office for National Statistics, 2015b).

Furthermore depression rates increase with age which can be due to a number of factors including physical health problems (Roberts, Kaplan, Shema & Strawbridge, 1997) and loneliness: 51% of people in England over seventy-five years of age live alone (NHS Choices, 2013), which means older survivors may need more support. Siblings also become more important in old age (Neyer, 2002). In addition, the older-

adults group may be affected by fewer variables; so for example people in this group are more likely to be retired and have already had their children, and those children are more likely to have left home. Younger age groups may have more variance, for example children, education and careers may occur at widely-varying ages. The time since the death occurred was due to be around five years, chosen as a middle-ground option from an overview of accessible studies on different kinds of loss, including co-twin, sibling and spousal loss (appendix six).

‘Older adulthood’ was initially used in this study to mean those whose current age was seventy and above. In our society older adults are classed as being sixty-five years of age and above (World Health Organisation, n.d.), so for the study of loss in older adulthood, the aim was to allow a five year period since the death; this meant participants could have lost their twin at sixty-five years of age or older. However, in the end, whoever offered to participate had to be recruited and this resulted in ‘older adulthood’ in this study encapsulating those whose age at loss was 51-84, which may have affected the results. This is discussed in chapter four.

2.5.2 Situating the Sample

The following information about participants (see table 1.1. overleaf) was collected in anticipation that it may have affected how the loss was experienced. Those factors were chosen as, while some past research on twins states they do not matter (e.g. Macdonald, 2002), broader work on bereavement states that they can have an impact on how one experiences and copes with the death of a significant person, as discussed in the literature review.

Table 1.1: Participant Demographics

Participant	Co-Twin	Gender	Current Age	Age at Loss	Number of Year's Since Loss	Cause of Co-twins Death (including type e.g. type of illness, type of accident)	Raised Together or Apart?	Ethnicity	Religion	Location
Sarah	C	Female	58	55	Almost 3 years	Illness-Alzheimer's disease	Raised Together	White-British	None	Brighton
Jack	R	Male	82	80	2 years	Illness-Mouth Cancer	Raised Together	White-British	Christian	Cumbria
Maria	N	Female	79	77	2 years	Illness-Heart Failure	Raised Together	White-British (English)	Church of England	Essex
Jill	B	Female	90	84	5 years and 9 months	Illness-Stomach Cancer	Raised Together	White-British (Half Irish, Half English)	None	Wales
Eleanor	MP	Female	79	70	9 years ago	Illness-Lung Cancer	Raised Together	White-British	Church of England	Stoke-on-Trent

Esther	O	Female	80	75	5 years ago	Illness-Infection during Leukaemia and Skin Cancer	Raised Together	White-British	None	Chislehurst
Mary	D	Female	78	73	5 years	Illness-Brain Tumour	Raised Together	White-British	Church of England	London (East)
Alice	E	Female	62	57	4 years	Illness-Kidney Failure	Raised Together	White-British (English)	Pagan	London (East)
Jane	M	Female	62	51	10 years	Illness-Pneumonia	Raised Together	White British (Half English, Half Scottish)	None	Yorkshire

2.5.3 Context

Twins were recruited from TwinsUK, the Twin Registry at St Thomas' Hospital, London. The Registry is the biggest twin registry of adult twins in the UK, comprising 12,000 twins who participate in research studying the genetic and environmental causes of age-related complex traits and diseases. As of 2012 there were seventy-one lone twins who were still active on the register.

2.5.4 Data Collection

1) Measures

A semi-structured interview schedule (appendix seven) was compiled, consisting of seven open questions, six is the minimum suggested for adults (Smith et al., 2009). These acted as a framework for the interviews. Semi-structured interviews were used as they are the preferred method of data collection in IPA, allowing participants to provide in-depth accounts of experience (Smith et al., 2009). Questions were devised based on sub-topics that arise in the quantitative literature on the matter (as there were no previous qualitative interviews to use as a base). The literature the questions were chosen from included Macdonald's (2002) study when devising the question about what the twinship was like and how twins saw themselves both before and after the loss. Woodward's (1998) and Withrow and Schwiebert's (2005) work also contributed to forming a question on the latter. For question six which included ideas about how twins felt others saw them, Piontelli's (2004) work, showing that how we see ourselves is reinforced by others, and Woodward's (1998) work was drawn upon. Lastly, ideas about coping mechanisms were derived from Macdonald's (2002), Bryan's (1995) and Woodward's (1998) publications. Further details of the main studies listed here are found in the literature review.

This strategy was then triangulated by consulting the Lone Twin Network Charity-Birmingham, the Twin Registry-London and Dr Nancy Segal (an American evolutionary psychologist who has done a lot of research on twins and has a non-identical twin sister) for their opinions and advice. The former director of my Counselling Psychology Doctorate course advised that this chosen approach was appropriate. Dr Segal said she thought the questions were good and did not offer any changes to them. The chairman of the Lone Twin Network provided her feedback, commenting that she saw no problems with the questions except for the original use of the words 'your co-twin'. She spoke of how it was not natural to refer to one's twin that way and it was unnecessary. Her comments were taken on board and 'your co-twin' was replaced with 'your twin', as it was felt that the use of 'co-twin' was too formal.

Attempts were made to balance the items on the interview schedule by making them specific enough for participants to talk about the loss of their twin, but simultaneously be broad and open-ended enough for them to talk freely (Smith & Osborn, 2008) and for what they felt was significant to surface. The schedule began with more general, broad questions to build a rapport and get participants used to talking in this unfamiliar interview situation (Smith et al., 2009), but questions were used flexibly in a manner that seemed logical in the moment with each particular participant. Trainee Counselling Psychologists are well-placed to engage in this process, but an awareness was present that the interactions were not therapy sessions and that caution was required not to create a therapy dynamic. The more sensitive questions were left until later in the interview, when it was hoped that the participants would have become more relaxed (Smith, 2008) and accustomed to the interview process.

2) Pilot

A pilot test was carried out in order to pre-test the interview schedule and look at the order and wording of the interview questions. The pilot interview was transcribed and a preliminary analysis was carried out, in order to examine whether rich enough data was being produced. It became apparent that perhaps it was not, and the interview schedule was altered slightly, the final version comprising seven questions and including additions about possible continuing relationships with the deceased, the meaning of being a twin, and a direct question about what it was like to lose the co-twin (appendices seven and eight). The opening question was also made broader. The rest of the interviews were then carried out from January 2015 to May 2015 and were transcribed over three months.

The aim was for interviews to last approximately one hour. Smith and Osborn (2008) state this is usual, and it was felt to be roughly sufficient. The choice was informed by the counselling context, in which this amount of time potentially provides long enough for the participant to become comfortable with the interaction and begin opening up. However this time period was flexible depending on how participants responded and time was made after each interview to allow participants to calm themselves and ask any questions, and to allow for a debrief. Interviews ranged from thirty-one to one-hundred and twenty-five minutes.

3) Procedure for Data Gathering

Potential participants were contacted via The Twin Registry at St Thomas' Hospital, London. There were seventy-one lone twins still active on the register. All seventy-one were contacted. Those who responded were sent an information sheet informing them

of what the study involved (appendix three) and what their rights as participants were, allowing them to think about what the study involved and whether they wanted to take part. These sheets were given to them again just prior to the interview, as were informed consent sheets (appendix four). As participants were recruited, dates, times and locations were organised for the interviews to be carried out. Interviews (digitally audio-taped, with consent) were carried out at the Twin Registry or at UEL. An examination of the interview questions can be found in the discussion chapter.

2.5.5 Data Analysis

IPA involves transcribing accounts verbatim, reading and re-reading them, noting face-value descriptive comments, comments about language used, and abstract concepts that emerge, followed by analysing each line of a transcript and identifying themes (Smith et al., 2009). Connections between themes are then made through the processes of abstraction and subsumption, so that super-ordinate themes are created (Smith et al., 2009). The process is repeated for the remaining cases, attempting to not let ideas emerging from the first analysis influence subsequent ones, so that new themes may still emerge (Smith et al., 2009).

1) Transcription

The interviews were transcribed verbatim (appendix nine) and in order for the transcripts to reflect the original interview as far as possible, non-verbal communication such as laughter and pauses (Smith et al., 2009) and verbal noise such as ‘umm’ were all included in the transcription for analysis. However, participants’ names, names of other people and places, and any other identifying information were altered in the transcription to protect identity and privacy and to preserve anonymity.

A key was devised detailing which pseudonyms corresponded to which participant and has been kept separate from the transcripts. This key will be destroyed once the research and assessment have been passed.

2) Reading, Re-reading and Initial Noting

As IPA is an idiographic approach (Shinebourne, 2011), the analysis initially focussed on examining each interview separately through engaging in an interpretative relationship with each transcript. The analysis loosely followed Smith, Flowers and Larkin's (2009) IPA analysis approach; they state that their recommended steps are not prescriptive, and for the novice IPA researcher can be worked with and adapted when the novice feels comfortable and the data necessitates it.

The pilot interview was transcribed first, then read while listening to the audio-recording. On subsequent readings, this allowed for the participant's voice to be imagined while the participant's words were read (Smith et al., 2009) and the associated voices became somewhat mentally present (Smith & Dunworth, 2003), which helped produce a comprehensive analysis (Smith et al., 2009). The transcripts were printed in landscape format, with a small margin on the right for anything of interest and for initial thoughts and comments (Smith et al., 2009), including text that captured attention, speculations and associations, as at that stage of the analysis the aim was to stay close to the text and its meaning (Smith & Dunworth 2003; Langdrige, 2007). More interpretative notes on how and why participants had these concerns were then recorded and included examination of language used (Smith et al., 2009), particularly, in the current study, metaphors.

3) Developing Emergent Themes and Creating Super-Ordinate Themes

Themes were drawn out from the initial notes made, and were formulated as words or phrases that reflected both the participants' words and subsequent interpretations made from examining them (Smith et al., 2009). These themes then needed to be drawn together, so related themes were clustered together. 'Abstraction' and 'subsumption' helped with this process (Smith et al., 2009, p.96-97) (appendix ten). Each of the initial themes were first noted on sticky strips of paper that could be moved around and regrouped. Later on, in analysis of all the transcripts, a preference to work with lists and group these using different colours was developed, and then reverting back to using sticky strips to group and re-group subthemes again.

The above was completed for subsequent interviews ensuring as far as possible that ideas from the previous interviews were bracketed, trying to allow for new themes to emerge (Smith et al., 2009). A table of master themes and subthemes was compiled where significance of a theme was shared across accounts (Smith & Dunworth, 2003) as far as possible. Quotations chosen were checked and re-checked to ensure the most appropriate quotation was chosen to match the theme and was placed in the table (appendix eleven). Theme labels were also sometimes relabelled at this stage (Smith et al., 2009).

2.6 Reflexivity

The analysis was carried out over a period of approximately six months. The process was somewhat draining at times, as initially I felt I was not finding anything new in the data. I also struggled with clustering themes at times. Time away from the transcripts was required at different periods so that I could view

them with fresh eyes. The process also highlighted problems with interviewing technique, and prompted me to think about the final themes and why these had been chosen, which is reflected on in the discussion.

Supervisory support was extremely useful at this stage and helped me to persist and focus in different ways, as well as encouraging me to think about and see things from different angles. At times it felt somewhat painful to discard extracts that I had originally wanted to use. Reflecting on why this was is interesting in itself too, but is beyond the scope of this thesis.

My assumptions undoubtedly influenced the research question, interview schedule and data collection, including manifesting at times in my prompts or lack of follow-up on what participants had said. This in turn would also have affected participant responses in different ways, therefore affecting the findings (Finlay, 2002).

Although I attempted to reflect upon my assumptions prior to conducting the research, the self is still brought into the research, particularly as one might argue that these assumptions can only truly be known and set aside when they become apparent through understanding participants' experiences (Smith, 2007). Through the analytic process I discovered that participants' accounts most strikingly focussed on an embodied attachment and embodied experience.

In terms of personal reflexivity (Willig, 2013), I am not a twin so I do not have personal experience of what this kind of loss is like. I have experienced

bereavement of people I considered close to me, namely the loss of an aunt and an uncle with whom I felt close emotional ties. I have also encountered bereavement in my client work, which bridges my clinical work and research, as the skills I used in bereavement work in counselling aided the interview process. I also worked with one twin who felt she could not confide in her co-twin. I held ideas about what co-twin loss is like, but these arose from imagination, and from observing the bond between twins both directly in twins in my extended family and through watching documentaries and reading, including material written by twins themselves and research studies. These preconceived ideas had the potential to affect the research and the interpretation of data, for example. In an attempt to limit this, I consciously tried to implement 'bracketing' (Husserl, 1927 cited in Smith et al., 2009, p.13), and going back over what I had interpreted, contemplated reasons for interpreting in the ways I had, as well as thinking about how interpretations might have been made differently.

Thinking further about personal reflexivity, the way I view myself and what I feel has become and is important to me *is* the self and my identity. I therefore had my own assumptions about twin identity that I had to try to keep at bay. For me, identity has been important for a number of reasons which I had also explored in personal therapy. Personal identity has many different dimensions, but key to me are my racial and national identity, coming from what may be considered a large nuclear family and trying to establish oneself among many siblings. Being from a mixed race background and an unusual mix has always been a conversation-starter, which I feel then became internalised and partly defines me. Being one of five female siblings is also often another hot topic of

conversation, and again I feel this has become ingrained in me over time. Having so many siblings, I also experience a battle to establish myself in the family, and from this another dimension of identity emerges. While the dynamics of sibling relationships change over time, I feel for me they have also been a defining feature of who I am today. I feel the last major influence on my identity is Western society, as it promotes individuality rather than the collectivism of many eastern cultures (Kim, Triandis, Kagiycibasi, Choi & Yoon, 1994). All of these contribute to how I originally thought about twin-sibling relationships prior to the research, including assumptions that most twins have close relationships, like and get along with each other, that the twinship forms a major part of self-identity, and that it is hard for twins to be individual. This could impact the data analysis and conclusions as there were expectations of closeness, of a strong and unique bond and an entwined sense of self, these expectations could influence how the data was analysed, with a bias towards these ideas or towards ‘seeing’ these.

The final master themes and subthemes presented in the analysis chapter are supported by verbatim quotations from the transcripts. They have been presented in a sequence that provides a meaningful narrative about the lived experience of losing an identical co-twin in older adulthood.

2.7 Concluding Comments

This qualitative research takes a hermeneutic-phenomenological epistemological approach. It used purposive sampling that is homogenous, to a degree, to recruit participants to engage in semi-structured interviews. The interview transcripts were

analysed following Smith et al.'s (2009) steps as a framework and guide. The analysis is presented in chapter three and the implications and limitations of it are outlined in chapter four.

Chapter Three: Analysis

3.1 Overview

The analysis chapter presents the results of IPA semi-structured interviews with nine female participants and one male - all members of TwinsUK, the biggest twin registry in the UK - to explore what the experience of losing an identical co-twin in older adulthood is like. Five master themes and eleven subthemes were identified (see table 1.2 overleaf).

Table 1.2: Master Themes and Subthemes

Master Themes	Subthemes
The Twin Relationship	‘You are a part of each other’
	‘We were always just called “twinny” ’
Embodiment	‘It is like your right arm being there’
	Embodiment of Separation
	Violence: ‘It is like you have been knifed’
Separation	Presence of an Absence
	The Divided Self
Preservation of a Connection	Continuing Bonds
	Trying to Keep the Co-Twin Alive
Grief Comparisons	Co-Twin Loss as Different
	Co-Twin Loss as Worse than Spousal and Sibling Loss

Research Question:

How is loss of an identical co-twin in older adulthood experienced by the surviving identical twin?

3.2 Introduction to Themes

The five master themes that emerged from the data illustrate participants' accounts of what it was like to be a twin, the experience of the loss of their co-twin and how they processed the loss experience.

The first master theme focusses on the twin relationship, and highlights the described unique bond between twins, as well as encompassing their accounts of being connected or having a sense of being united as a pair. It also reflects that the twins felt society reinforced this sense. The second master theme, Embodiment, aims to capture the embodied relationship, meaning the physical manifestation of the twin relationship, and to consider how this triggers the loss to manifest not only psychologically but also physically. This theme also encapsulates how the loss is managed through the body, and a powerful 'violence' metaphor also emerged in descriptions in this theme. The third theme, Separation, explores participants' experience of the loss as a separation, a feeling that something is missing and that the self is divided, and that a new aspect of the sense of the self has to be adapted to. The fourth master theme, Preservation of a Connection, reflects how participants managed the loss and explores how they experienced an ongoing relationship with the deceased through a process of continuing bonds. Variability was present in participants' accounts of this: some noted the continuance of the twin identity and others illustrated the relationship after death as being different from the relations with others such as a

deceased spouse. A need to try to keep the co-twin alive also seemed apparent and it appeared that this was not acknowledged or recognised by lone twins as unusual in any way or as an unusual part of the grief process for them. The final theme, Grief Comparisons, explores grief comparisons across different loss experiences and suggests that co-twin loss is a unique type of loss. Within this theme, loss of a co-twin was identified as being different from spousal loss in particular. Some participants' accounts suggested it was different from the loss of a non-twin sibling and different from other losses in general. One participant's account documented co-twin loss as being worse than spousal loss.

3.3 Master Theme 1: The Twin Relationship

This theme captures an idea of how twins reported feeling that they were a part of each other, which is explored in an emotional way in this theme. It also conveys how participants experienced being a twin and how they felt they were treated and perceived by others, and documents participants' experiences of being treated as a unit.

The participants were directly asked about their relationship with their co-twin in an attempt to ease them into the interview and to establish a context for further exploration of the unique experience of co-twin bereavement. Examination of the material that emerged in the study reveals that they provided specific accounts in which the depth of symbiosis within the relationship can be seen, and we shall begin exploring these below under the first subthemes. This theme is important as it sets the context for the loss experience.

3.3.1 Subtheme 1.1: ‘You are a part of each other’

This subtheme captures descriptions of twins feeling that they were connected to their co-twin. The subtheme focuses on this in an emotional sense.

‘You know, she, she is there

(Mhm)

You know, she is part of, part of you’ (Esther, p.28, lines 880-882).

Above, Esther noted the presence of the co-twin creating feelings of being joined or united. Repetition of the words ‘part of’ emphasises a connection and the phrase ‘part of you’ illustrates a strong attachment.

Esther further stated that her co-twin is ‘not a sister’, suggesting a twin sister holds a different meaning for her, and in this context she suggests that her twin sister holds some sort of higher status or greater meaning for her:

‘it is not a sister, it is part of you, you are part of each other’ (Esther, p.14, line 418).

Her explanation that the relationship is different to that of non-twin sibling sister relationships because as twins ‘you are a part of each other’, perhaps suggests a closer emotional bond and an enmeshed sense of self.

Similarly, Eleanor's account also documented this idea of being a part of each other, which was expressed as feeling that they were two halves, which could suggest that together they form a 'whole' and are thus then complete:

'she was, not just his, sister in law...she was the other half of me...she was the other half of me' (Eleanor, p.42, lines 1328-1329).

Repetition of the phrase 'she was the other half of me' perhaps also emphasises this kind of seemingly unique felt connection.

From this subtheme it is apparent that twins feel an emotional connection through which they feel a part of each other and which unites them. This sense of unification and wholeness is intrinsically linked to the next subtheme, which explores how others also contributed to this sense of joining.

3.3.2 Subtheme 1.2: 'We were always just called "twinnies" '

The views of others around us contribute to shaping who we are and it can be seen that how twins felt they were treated by others and how they felt others perceived them was significant for the way in which they saw themselves. Many participants spoke of how they felt 'other' people did not treat them as individuals.

Maria illustrated this directly:

'you were not treated as an individual, you were treated as whole' (Maria, p.10, lines 304-305).

The use of the term ‘whole’ suggests that they were not treated as separate entities in their own right. Maria’s account illustrates this symbiosis further, noting that they were both called ‘twinny’ rather than being referred to by their actual names:

‘at school you are always treated as a “twinny”’ (Maria, p.9, line 286)

and

‘You are one of “the twins”’

(OK)

or “the twinny”’ (Maria, p.10, lines 292-294).

Sarah reported the same experience and the same term or name used:

‘Yes, in fact we were always just called “twinny”, rather than by our Christian names

(Mhm)

It was just “twinny”’ (Sarah, p.3, lines 76-78)

Eleanor also reported this, but in a slightly different manner. She noted that she and her co-twin were referred to as ‘the P twins’ and that this also continued into adulthood:

'right up to then, we were still "The P twins", weren't we?' (Eleanor, p.23, line 721).

Jill also experienced this:

'She (mother) always referred to us as "The Twins" she never referred to B and Jill

(Mhm)

It was always "The Twins" ' (Jill, p.4, lines 106-108)

as did Jane:

'Because you are, you have been referred to as "the twins", particularly if you were brought up like I was' (Jane, p.12, lines 347-348).

Although this can occur within non-twin sibling relationships, for example being referred to as 'the girls' or 'the boys', this often comes from other adults, whereas in the twin relationship being referred to as 'the twins' is likely to come from a wider group including peers, which is also suggested in Jack's comment:

'At school, there, there, I used to er, I used to, er maybe thirty years or forty years afterwards, I would recognise somebody and er "Oh yes" they would say, "You, there was two of you wasn't there" ' (Jack, p.6, lines 169-170).

The above also shows that this reference continued throughout life. Jack also stated that one was identifiable and remembered because of being a twin and in the above, he also emphasises a lack of individuality and separateness, perhaps encouraging or reinforcing a shared sense of self or defining oneself in relation to the other to a great degree.

This is seen further in the following;

'People would come to me and say "Are you you or your brother!?" ' (Jack, p.5, line 132).

There was also an air of 'specialness' about being a twin, for example Jack compared the experience of being one of twins to that of being a film-star in that being identical made you distinguishable:

'You are almost like a film-star, everybody looks at you' (Jack, p.4, line 114).

The term 'film-star' is an interesting one, suggesting being an object of attention and being different from the ordinary person, as if being twins gave them a kind of celebrity-status and that everybody knew who they were. However, the tone in which this was expressed was one that seemed factual, and there did not seem to be positive or negative emotion attached to it. This perhaps suggests that it was something that had become 'normal', although just prior to the excerpt, JT did document it as an advantage.

Two participants also observed that parents contributed to this sense of ‘specialness’:

‘Actually my mother was so proud of having twins’ (Jill, p.4, line 99).

The thought of someone being proud in this sense, as Jill noted feeling that her mother was proud of them because they were twins, could have an impact on one’s sense of self. This could have the effect of wanting to maintain a twin identity in order to feel valued or make one’s parents proud. The fact that Jill notes this perhaps indicates that it was something she directly observed from her mother, which created or reinforced a feeling of being special. Kendler, Gardner and Prescott’s (1998) findings suggest that twins experience a sense of ‘specialness’ and that identical twins do more so than non-identical twins. Klein (2003a, p.13) noted that in her research some twins were given the message that being twins meant they were ‘incredibly special’ and that this message is most often received from parents.

Eleanor’s account also reveals this, and she also used the concept of pride in relation to her father’s feelings about her and her sister being twins:

‘And he (father) used to take us to see our grandmother, which was his mother

(Mhm)

Er, on a Sunday morning and we walked, and it was quite a distance but we walked with him. And he was the proudest man going, walking, to granny’s

(Mhm)

Holding a twin on either side

(Mhm)

And people stopping him, he was as proud as punch my dad was

(Laughs)

And we, we used to say, "Come on dad, come on dad"

(Laughs)

Because people would stop and talk

(Mhm)

*And they would say "Which one is this?" Or, or they would say, you know,
"Eleanor" to me and, and, or they would say "MP" ' (Eleanor, p.4, lines 98-112).*

The phrase 'proud as punch' used by Eleanor also illustrates a sense of great delight and pride. Eleanor noted that people would stop her father and question him about which twin was which. Again this illustrates the attention drawn to them because they were identical twins. Reference to people saying 'which one is this' in Eleanor's

account also creates an impression of an absence of individuality and a feeling of a lack of separateness and an implied sense of joining, for example in thinking about being one of a number, in this case of two, that can form something complete.

Eleanor's excerpt also notes the confusion people displayed when trying to identify them, which in turn could have had an influence on the sense of self.

Eleanor also spoke about her mother not wanting her and her co-twin to be separated at school, perhaps again reinforcing the idea of a joined sense of being;

'And at school, we were so alike they tried to separate us but my mother would not allow it. They wanted to put us in different classes when were in the senior school

(Mhm)

And my mother would not allow it' (Eleanor, p.2, lines 45-48).

The words 'not allow' and the repetition of the phrase 'my mother would not allow it' could depict a sense of control and domination in the mother's desires. Although these ideas and classroom non-separation were common in the 1950s, more recently this has changed and the importance of individual development is now recognised (Klein, 2003a). As the sample in the present study mainly consisted of older adults, the remarks could reflect the difference in attitudes towards schooling and separation apparent and commonplace in society then and now.

Eleanor also hinted at her mother reinforcing a sense of ‘sameness’ in the following remarks:

‘my mother used to sit, just sit and smile and she used to say you are just like looking in a mirror you two’ (Eleanor, p.7, lines 206-207).

Jack’s account also documented a sense of self as deriving from the perceptions of twinship expressed by his mother:

‘You are something together and nothing parted’ (Jack, p.1, lines 6-7).

This could perhaps imply that they do not function well apart, or that they are not considered to exist unless they form a whole.

This idea was also reiterated by Jane’s Girl Guides Leader:

‘you two are useless apart but very strong together’ (Jane, p.20, lines 589-590).

Lastly, Alice observed being treated differently and the presence of a lack of separateness, in her description of gift-giving to her co-twin and herself, compared with that to a singleton sibling:

‘And we have a younger sister, three years younger and our birth, birthday parties, people would turn up with two presents, you would expect one for me, one for E. We got one

(Mhm)

SH got another and erm when we asked, “Oh well there is one for her, there is two of you, she might feel left out” ’ (Alice, p.5, lines 133-137).

The phrase ‘there is two of you’, as in Jack’s account, suggests a lack of a sense of individuality or of the twins as separate people, almost depicting a state in which being a twin and an individual are mutually exclusive.

Alice’s illustration of her own expectations, namely that she and her twin should have received separate presents, may provide us with insight into her feelings, suggesting that she felt they were not but should have been treated as individuals celebrating their birthdays each in their own right. The fact that she also goes on to say that they did question this action perhaps suggests it did not sit comfortably with them.

Furthermore, the thoughts and views of others are depicted and Alice notes feeling ‘pissed off’ (Alice, p.5, line 142) at the reasoning provided to her and her co-twin, and that her co-twin was the older twin and therefore in ‘control’ and ‘possession’ and perhaps she actually felt left out. The response of others in ‘oh well’ (above) also suggests a dismissal of Alice’s feelings and lack of consideration of the way the twins may have felt left out as well as the younger sister.

This subtheme shows how twins felt they were treated as a pair and how attention was drawn to the self because of being a twin.

Theme One examined how twins felt they were connected in that they felt they were a part of each other, with discussion focussing on the emotional aspects of that theme. In addition, the theme explored how twins felt they were treated by others, which also contributed to how they experienced their twin relationships. These experiences of the twin relationship, and the sense of self that seems to arise from these experiences, are indicative of a close-knit bond. This may be typical of the types of accounts that twins provide of being a twin, for example research has shown that twin siblings are more likely to regard their twin than their non-twin siblings as an attachment figure (Tancredy & Fraley, 2006) perhaps indicating a different and stronger bond between twins. This could provide a context for the experience of bereavement in co-twin loss and is intrinsically linked to the next master theme, which encapsulates how the loss is experienced in the body. This next theme relates to a connection and unified sense of self but on a different level, namely that of the physical.

3.4 Master Theme 2: Embodiment

Here, embodiment draws upon the idea of our thoughts, feelings and behaviours being grounded in our sensory experience and our different bodily states (Meier, Schnall, Schwartz & Bargh, 2012). This view reflects the ideas of Merleau-Ponty who stated that we engage with the world through our bodies and that the body is always located within lived experience (Smith et al., 2009). The term has also been rephrased more simply as ‘the sense of one’s own body’ (Longo, Kammers, Tsakiris & Haggard, 2008, p.979). Ideas about embodiment within twins seem to have been explored only in relation to conjoined twins who are physically joined via the body, and experiences of embodiment in people who are genetically identical have been largely neglected (Prainsack & Spector, 2006). Research by Cassam (1997) and Edelman (2004)

explored ideas of embodiment relating closely to one's sense of self, which can be directly seen in subtheme 1.1. Here, twins explored feeling physically a part of the co-twin, a feeling that related to their sense of self and was spoken about in an embodied way, as will also be seen in the subthemes to follow which document how the loss was felt in the body as a result.

3.4.1 Subtheme 2.1: 'It is like your right arm, being there'

This subtheme is representative of the embodiment of the twin relationship experience and most strikingly of an embodied attachment. Embodied attachment here, is referring to an attachment that is felt within the body in a physical sense, and it is this physical connection that is the focus of this subtheme. Perhaps it is this embodiment in the twin relationship, and the way in which the relationship is expressed and valued in the body, that highlights the twin relationship as being significantly different from any other relationship.

'you are part of each other, you are, you have got the same genes, you..you think alike..you know' (Esther, p.14, lines 418-419).

Esther described being connected and also made reference to the genetic link present in identical twins, from which she inferred a different and stronger level of closeness than that apparent in other relationships. She also went on to say that she has always felt she and her twin were connected in this way, and that she sympathised with non-twins as not having this depth of connection:

'I had always felt that, that, that, that, that the two of us were, you know, a part of each other and I, I feel..also sorry for people on their, on their own' (Esther, p.11, lines 327-328).

Esther used the phrase 'you know' in both excerpts, and it appears in her transcript 423 times, perhaps suggesting that she expects others to know these things, or that it is likely to be common knowledge, and perhaps also expressing a sense that what she is describing is common across identical-twin pairs in her experience.

Jack's account, like Esther's, also made reference to the genetic link between identical twins:

'Erm..we were biological identical

(Mhm)

We were, we were, we were, it was one egg

(Yes)

That split

(Yes)

And became two..it was not, there are twins that are not identical

(Mhm)

But we were identical twins and er, that did make a difference to us because, I, I would know how he felt about things, he would know how I felt about things' (Jack, p.21, lines 647-656).

This adds a different dimension to the idea of being entwined, illustrating the connection from conception and the splitting of a whole. Jack's account mentions the splitting of the egg, the biological mechanisms of which are unknown and remain a mystery (Bryan, 1983). The term 'split' also suggests former unification and evokes the unique bond there once was, suggesting that from this an exclusive bond continues to unite them, one that is not shared by other beings including non-identical twins. In Prainsack and Spector's (2006) research, a twin participant also spoke about this and similarly described being told that the twins originated from one egg that split, meant that the participant felt this led to a stronger bond.

The use of the term 'split' and its evocation of binding can be linked again to the idea of being a part of each other in subtheme 1.1. Jack's account suggests that there is something about the unique relationship of being an identical twin itself that creates a connection with the co-twin on an emotional level, a connection that the participant felt was unique to the twin relationship, specifically to the identical twin relationship. He expressed his sense that the felt connection was a result of a physical, biological connection and of being identical.

'it must be strange for other people not being a twin..to, understand that depth, of er..being, part of someone else' (Maria, p.20, lines 620-621).

In the passage above, Maria spoke about the uniqueness of the twin relationship, feeling it could not be experienced or understood by other people and that it holds an almost special quality which has a 'depth' to it. The use of the term 'depth' as a measure of being part of someone else may refer to the intensity, strength or degree of being part of the other, which perhaps implies a great or deep connection with the other, that could also be thought about in an embodied way.

Maria also went on to say that in her experience she and her co-twin shared their lives with one another. This was described in a simile of her twin as her right arm, depicting the enmeshment present:

'you are sort of living..part of her, her life and she shared my life..yes, if you think about it...I suppose it is, well I suppose it is like your right arm, being there..' (Maria, p.20, lines 614-615).

Maria's reference to the 'right arm' in comparison to the co-twin illustrates an embodiment of attachment, and it could suggest that the 'right arm' is always there, as if one can always count on it, and therefore on the co-twin, to be there.

Jill took a slightly different stance in her account, emphasising that, having been a part of one another, she found that the loss gave rise to a new situation of having to live as an individual:

'well of course, you cannot explain, you do not know what it is like to be single without being, having a some-, a twin' (Jill, p.4, lines 120-121).

This also suggests that she has never perceived herself as a single person.

Eleanor described her co-twin and herself as 'soul mates' (Eleanor, p.18, line 546). Although at first reading this may not seem directly to be about being a part of each other, that sense could be contained in its meaning. One's soul mate is often thought of as a special person who perfectly complements one's identity (Arnett-Jensen, 2011). Within this ideal is the sense that one feels completely at ease with one's soul mate (Arnett-Jensen, 2011).

In the general use of the term 'soul mate' in spousal relationships, two souls are often thought of as uniting when a marriage takes place, and the Torah states: 'A man should therefore leave his father and mother and be united with his wife, and they shall become one flesh' (Genesis, 2:24). Sikhism reveals a similar view: 'They are not said to be husband and wife, who merely sit together. Rather they alone are called husband and wife, who have one soul in two bodies' (Guru Granth Sahib, p.788). Piontelli (2008) explored ideas of twins as soul mates. She described that in her research she felt that twins were the closest one could get to the ideal and permanent soul-mate (Piontelli, 2008). In further discussion later, it can be seen that some participants explored comparisons between spousal and twin relationships, some saying they felt a different and deeper bond lying within their twin relationship than in their spousal relationship. However, one might also consider ambivalence in some twin relationships: Klein (2003b), for example, noted that twins sometimes feel

intense dislike for each other and feel burdened by one another. Much of the psychoanalytic literature documents twin relationships have the potential to be so intense that some twins express wishes to kill the co-twin (Lassers & Nordan, 1978).

Within the idea of twins feeling that they are a part of each other, participants' accounts also illustrated experiences that seem to be unique to twins and may suggest a special link between them. Many accounts included examples of these seemingly unusual experiences, which appear to constitute an embodiment of attachment as a representation of the unique relationship. For example, Alice spoke about feeling stomach pains when her twin sister was giving birth:

'And I got back to KP about two weeks later to find that was the month she had the baby..and the exact time with the erm, around the same time

(Yes)

I was having terrible pains in my stomach. When she had her son, I was in NT and she was in D and erm..I felt very uncomfortable all night' (Alice, p.7, lines 196-200).

Esther relayed similar experiences:

'I know that sounds odd but..you know, but erm..and, and, if, if she was ill, you know, you, you, you, you erm....you felt..you felt ill' (Esther, p.28, lines 858-859).

These accounts could suggest there is something that twins experience that is unique, something in the nature of the twin bond, and further that perhaps there is a deeper connection than in other relationships, one operating on different levels - mental, emotional, physical - that unites them in some way. In Alice's and Esther's accounts this sounds almost like a physical telepathy. A case report by Budur, Mathews and Mathews (2005) describes a similar effect, with particular reference to Couvade Syndrome which occurred in twin sisters rather than a spousal relationship. Pector (2002) too, in her review of the literature on cultural practices related to twins, noted that the Yuma tribe in North America believe in a sympathetic twin bond.

Another participant spoke about illness and a twin connection in a slightly different manner, recalling both twins undergoing the same experiences simultaneously:

'Right, so we are in our separate cookery classes..I had passed out in this class (points to right), C passed out in this class (points to left), and we ended up meeting up the first aid room

(At the same time?)

at the same time..how weird is that' (Sarah, p.5, lines 134-137).

Sarah expressed her surprise, and sense of a strangeness in the event, as if she felt there was something unusual, almost magical, in her bond with her co-twin. Perhaps this situation could also be thought of as a form of unconscious mimicking of one another.

Lastly, some participants stated that they shared the same thoughts as their co-twins, perhaps suggesting a further level of connection, that colloquially referred to as ‘mind reading’:

‘with a twin it is easier to think of their feelings because their, your..her feelings and mine were virtually the same, we thought the same things’ (Esther, p.17, lines 514-515).

Mary’s account also illustrates this:

‘Directly I picked the phone up and we were talking to each other, we knew exactly what each other thought, in a way. I would say, ‘What did you..what did you think last night of that woman, and that..and that show?’ And what she said was the same as what I thought.’ (Mary, p.19, lines 591-593).

There is a felt connection within the twin relationship on several levels here: physical, mental and possibly spiritual. It could be that the embodiment felt within the twin relationship is a precursor to the loss being experienced and felt across an embodied dimension. It may trigger the loss to manifest physically in the body, which leads this discussion to an exploration of embodiment in relation to permanent separation through death.

3.4.2 Subtheme 2.2: Embodiment of Separation

This subtheme reveals how the experiences of loss were felt in the body. Alice described various elements in relation to this subtheme. First she explained that she

felt as if she had lost half of herself, rendering her an ‘abnormal person’. For her the ‘sensible’ side of her was missing: earlier she had reported that her co-twin was the more sensible of the two of them and that this part was gone, conveying a sense of embodiment in that her co-twin had been a part of her that had died, a part of her body and a part of the self that had died:

‘I feel like I have lost half of me..and, the sensible half..erm..I feel I, I am not a normal person anymore. I may look like a person but

(Inside)

...That side of me is missing. But I can actually feel it, in my brain

(Mhm)

In my body and I feel as if that, side is somewhat numb

(Mmm)

But that side is still living’ (Alice, p.14, lines 421-429).

Alice’s tone was full of sadness, she was also teary when relaying the above, highlighting her grief but also perhaps emphasising that she is grieving a loss of a part of herself.

For Jane the loss manifested in the body in terms of her eating disorder returning:

'it was very very dark time, um, you know, indescribably dark really, both physically and um, because I had um, my eating disorder kick back in' (Jane, p.3, lines 65-66).

Eating disorders are often thought about in terms of gaining control when one feels out of control (Lawrence, 1979). Jane's eating disorder returning could represent the embodiment of separation in the sense that the pain is managed in the body by taking control of food intake. Jane's use of the phrase 'indescribably dark' suggests a great degree of unpleasantness and unhappiness, to such an extent that words cannot describe how she felt.

Eleanor described feeling the pain of the separation in her body in a metaphor:

'It is like a heavy weight between my breasts

(Mmm)

It is like a heavy stone' (Eleanor, p.48-49, lines 1526-1528).

She described the pain of the loss in an embodied way as it was felt in her chest, perhaps suggesting heartache. Embodied grief manifesting as heartache is not unique to co-twin loss: Gudmundsdottir (2009), for example, documented it occurring in bereaved parents; however Eleanor's description of the pain as 'like a heavy stone',

and her repetition of the word ‘heavy’, could indicate the strength and depth of the pain felt, which may differ in comparison to other losses.

This subtheme demonstrates how these bodily experiences can be felt as unpleasant and painful, a situation that leads us on to described experiences of the separation, with a focus on the violence felt within it as another dimension of embodiment.

3.4.3 Subtheme 2.3: Violence: ‘It is like you have been knifed’

Violence felt in the loss was prevalent in some participants’ accounts, and some powerful language was used. Jane compared the loss to being stabbed:

‘it is like you have been knifed. It is like you have been cut in half’ (Jane, p.2, lines 44-45).

The use of the term ‘knifed’ conjures up ideas of harm by force. It depicts the embodiment of the pain of the separation in that being ‘knifed’ is associated with pain, sharpness and cutting; the embodiment of this pain is seen in Jane’s description of feeling ‘cut in half’. The simile could also indicate the depth of the pain, given the sensations of piercing pain associated with being stabbed. Being cut in half also suggests the enduring nature of the pain and that the loss is finite, as well as creating a sense of the self being damaged or killed off and conveying a loss of a part of the self, which in turn could be linked to the idea of the twin pair being united as discussed under Master Theme One.

The embodiment of the pain is strongly illustrated in participants' use of language, particularly metaphor. Meier, Schnall, Schwarz and Bargh (2012) have noted that embodied processes are often depicted in language through the use of metaphors. Semino (2010) also observed this directly in relation to pain experiences, and Umphrey and Cacciatore (2014) documented that metaphors can help bereaved people describe and express their grief.

Jane's and Eleanor's accounts both illustrate loss being expressed as a metaphor of the self being torn apart in some way. Jane used the term 'ripped':

'Just like, you know, being ripped apart really' (Jane, p.24, line 708).

This feels strongly associated with violence: it creates a sense of breakage or forceful tearing, or even destruction, which is thought about in terms of the self being ripped apart, like a separation of a part of the self.

Eleanor used a slightly softer term, 'pulled apart':

'I do miss her, I, I do, I cannot tell anybody how, how much I miss her

(Mmm)

It is like..it is as if you are being pulled apart in a way' (Eleanor, p.26, lines 804-807).

This can be thought about in different ways, one being again as a piece of the self being removed or destroyed. The term ‘pulled’ also suggests the involvement of external forces in the separation, and says something about the bereaved’s lack of control in this.

Eleanor and Jane both spoke about the separation using the image of ‘cutting’. Eleanor expressed it as a cutting that creates a split: using a simile, she made it analogous to cutting a fruit in half and leaving half of it. This again involves the idea of half of one thing being left behind, indicating that the whole unit is made up of two of the same thing or similar halves, much as she perhaps experiences her sense of self. In the loss of her co-twin, half of herself is gone:

‘it is like cutting an orange in half..and eating one half and leaving the rest, that, that is what you do when you separate’ (Eleanor, p.60, lines 1888-1889) .

Cutting also indicates that an opening, incision, hole or wound is made in something. Violence is relevant here, as the act of cutting usually involves a sharp tool.

Jane used the idea of cutting in a different way:

‘It was a bit, it was a bit like sort of an electrical wire being cut really. You know, a bit like a current being cut off’ (Jane, p.36, lines 1077-1078).

She talked about cutting leading to the loss of something. Something also feels finite about the expression used: when an electrical wire is cut and the current or electrical

charge stops flowing, whatever the circuit was connected to does not work. Thinking about this in relation to Jane's loss of her co-twin, perhaps she is aiming to encapsulate the idea that part of her has died, that there is no life to that part, that something has stopped working or has been destroyed.

Eleanor's account depicted violence in a different way: she talked about ambivalence in the loss experience. She had been expecting the loss yet it 'hit' her, indicating it was a shock at the same time. Hitting can also be conceptualised as a violent act and may depict the pain:

'I was expecting it but it hit me' (Eleanor, p.11, line 328).

In Alice's descriptions of her experience, violence was present in yet another way and helps to provide us with some understanding of the pain she feels:

'she chose six o'clock in the morning to die, when they were changing, over staff, to be as little bother that she could possibly be...erm...and, it was like being punched in the stomach, in the face, together and my stomach is still, is doing that..' (Alice, p.20, lines 605-607).

She described the pain in a simile as comparable to being punched in the face and stomach simultaneously, the act of simultaneity emphasising the pain felt. The continuity of pain is also described as this feeling having remained with her and her emotional pain was depicted in her tone and the tears that were shed when she was relaying the above.

The expression of the pain of separation in an embodied and violent way in this theme encourages us to think about separation in the different ways it manifests for lone identical twins.

3.5 Master Theme 3: Separation

This theme and its subthemes capture something of what the loss experience itself was like for the participants. This is contextualised by the symbiotic attachment depicted in the themes so far. Twins placed an emphasis on feeling that with the loss, something was missing. Some participants also spoke about a division of the self in terms of being a twin and ‘becoming’ a singleton.

3.5.1 Subtheme 3.1: Presence of an Absence

Some participants’ accounts documented the loss in terms of feeling something was missing.

Jane described the presence of a hole:

“I do not normally say this to other people” she said “but I have got a hole where my twin was”. I went, “Mhm” and that is why I mentioned it, you know. Because it is like a hole, you know’ (Jane, p.25, line 748-750).

She could have been referring to a part of the self missing in an emotional sense. Use of the metaphor ‘hole’, suggests something is missing or lacking, almost an emptiness experienced as a void. What was also interesting in her description was that another twinless twin had described co-twin loss in this way and that Jane could relate to the

feeling, suggesting it is not unique to Jane. However, one must also consider that in other kinds of bereavements, loss is also sometimes described this way. For example Klass and Marwit (1988-89) noted that bereaved people often refer to notions of amputation, shattering or something being missing. Feelings of a loss of part of the self have been shown to be present in bereaved parents when they lose a child (Klass, 1988). This demonstrates that the feeling is not unique to bereaved twins, but the example may prompt considerations of the degree of feeling in relation to what is known about the twin bond from previous research and the accounts in this current study. If the nature of the co-twin bond is different, the experience of loss may also be different (Withrow & Schwiebert, 2005) and grief felt as more intense (Segal & Ream, 1998).

Eleanor's account also referred to the presence of something missing, illustrating that an empty space is left and that it was hard to adjust to:

“Oh, I will ring MP”, no, no MP

(Mmm)

And, and that void took, a long time to get used to... ’ (Eleanor, p.26, lines 810-812).

Esther spoke about feeling something was missing in terms of never having lived without her co-twin before:

'when I moved back to this house really, without O erm, you know, er, it was horrible. I know it is horrible for everybody, but, but for a twin who has never really been a loner, not one on their own' (Esther, p.24, lines 735-737).

She also interestingly used the word 'loner'. This term generally has a negative connotation and in her account she uses it in a negative way, perhaps revealing that she had felt sorry for singleton people. The focal point of 'loner' here is to emphasise that she has never known life without her co-twin and there is some acknowledgement that others experience similar feelings, but others' feelings are similar yet different, revealing ambivalence. She feels that having lived as a twin, she has never been a 'loner', or single or lone person. This could shed some light on how she sees herself and how she experienced the twin relationship when her co-twin was alive, possibly suggesting that her sense of self was entwined with that of her co-twin. This is described further in the following:

'I think it is, it is the fact that you have never been on your own, you have never been a one' (Esther, p.25, lines 777-778).

Maria's account echoes Esther's: they both explained that having been around the co-twin for the whole of their lives made it hard to begin to lead life without her:

'when you have been a part of somebody for seventy-eight years, it is seventy-eight years..it is difficult, you have never known life without them' (Maria, p.2, lines 53-54).

Maria emphasises the duration of time by repeating ‘seventy-eight years’ which highlights the long-established felt connection which continued throughout life. This was followed by the term ‘difficult’, suggesting a link between the longevity of their relationship and her experience of the loss. She then elaborated by saying that the co-twin loss experience was intensified by her feeling that she was a part of her co-twin, again highlighting the twin, united sense of self where perhaps an entwined sense of self and/or identity lies.

Sarah’s account presents a similar idea. She described the loss resulting in her no longer being a twin, saying that this ‘hit’ her:

‘because I was not a..(tut), basically I was not a twin anymore, um...so, that hit me...um, I, I knew it would, I knew it would..um, but I can remember things that, that we did together and, and, enjoy, the memory’ (Sarah, p.19, lines 601-603).

The use of the term ‘hit’ implies shock or a sudden occurrence and realisation. The sense of knowing that is expressed creates some ambivalence as it ‘hit’ Sarah, suggesting it was not expected, but she also described knowing that the feeling would come, simultaneously suggesting a sense of anticipation. Perhaps this itself can be related to the stage models of grief in much of the grief literature, which documents feelings of shock and denial (e.g. Kübler-Ross & Kessler, 2005), observing that even with expected losses people often experience these feelings, but that with unexpected loss the phase of shock is more pronounced (Brown & Stoudemire, 1983). ‘Hit me’ also implies an external force and a lack of control, reflecting a sense of sudden pain, which could also be thought of as embodied pain.

Jane spoke about loss in terms of her sense of self, but perhaps in a slightly different way from those already mentioned, as she specifically stated that part of her experience is about a loss of identity:

'I found very difficult, different, difficult and I still find difficult, people say, "Well you have got to think about yourself" you know, "You have got to look after yourself", and I was thinking, "Just a second. There is a bit of a problem there, because I have no idea who I am". It is not an identity, um, crisis. It is an identity loss.' (Jane, p.12, lines 342-345).

The fact that Jane reported that she does not know who she is may also suggest that her sense of self, as in other participants' accounts, seems to have been entwined with the co-twin in its formation. Engel (1975) explored identity loss resulting from loss of twinship in relation to these ideas, and Case (1991) documented the experience in terms of feelings of losing half of the self. Furthermore, Withrow and Schwiebert (2005) noted that this identity loss can be related to the presence of the co-twin since conception, a part of identity that has always been present.

This leads us onto the next subtheme, where the effects of loss on the sense of self are contemplated further and the ways in which this is manifested in how the self is experienced as a result of the loss.

3.5.2 Subtheme 3.2: The Divided Self

This subtheme explores how some participants experienced divisions and dilemmas within their self, feeling divided by the death of the other. This suggests that they were ‘made whole’ by the co-twin.

Alice spoke of feeling ‘disloyal’, speaking in the singular, suggesting a sense of unity and being part of the other:

‘I still talk with the “We” and “Our”, occasionally the “Me” or the “My” but I feel uncomfortable saying that

(What feelings does that bring up?)

Erm, I should not be saying that..I should be saying “Me” or “My” or “I” but I feel like I am being, disloyal’ (Alice, p.15, lines 449-452).

It appears she is experiencing a dilemma between what she ought to say and what she is choosing to say, perhaps feeling perplexed about which choice to make, and she noted discomfort in speaking this way:

‘Now I find it uncomfortable talking with the singular’ (Alice, p.15, line 457).

Eleanor spoke about a division of the self in a different manner in relation to this theme: she said half of herself ‘went’ when her co-twin died, suggesting the feeling of a loss of a piece of the self emotionally:

'My, my..my..better half went and..my, my other half went, which is MP' (Eleanor, p.48, line 1505).

Similarities were also present in Esther's account, revealing the sense of a bond or attachment that meant one has never been an individual and never felt individual, so that the loss brings up having to live in a way one has never lived before. She made comparisons to singleton people who lose a spouse, noting a singleton identity was present prior to marriage and it is a known identity, also noted by Woodward (1998), but that for a twin losing a co-twin, a new way of being has to be adapted to. This is illustrated by the following excerpt:

'perhaps it is a downside is that I have never learned to cope..with being a lone person

(Mhm, mhm)

You know, so I have never been a lone person, you know

(Mm, mhm)

That is probably a downside

(Okay)

Because, you, you know, erm, if you are a lone person, then you, at some time in your

life you have been a lone person so when you lose your, you husband then you, you are..I should think it would be easier to cope' (Esther, p.35, lines 1082-1089).

As a result of feeling division within the self, some participants managed the unfamiliarity of being a singleton, or the loss in general, through the idea of maintaining a connection with the deceased in some form, which is explored in the next theme in different ways.

3.6 Master Theme 4: Preservation of a Connection

The fourth master theme Preservation of a Connection, captures what seems to be a need to maintain some form of a continuing relationship with the co-twin as another way of managing the loss.

3.6.1 Subtheme 4.1: Continuing Bonds

Grief research has shown us that continuing bonds with the deceased can be observed across many cultures: in Japanese culture, for example, a deceased family member becomes an ancestor to be worshipped (Klass & Goss, 1999). Continuing bonds have also been shown to be present across a range of relationships, for example in parent-child relationships, conjugal relationships and sibling relationships (Klass, Silverman & Nickman, 1996). However, some participants in the current research spoke about ambivalence towards continuing bonds, reporting that they knew their co-twin had died yet felt that he or she had not died. This challenges traditional ideas of griever's needing to move on and break bonds with the deceased (Steffen & Coyle, 2015). Eleanor's account illustrates the ambivalence well:

'I cannot feel, that my sister..is..she is dead, I know she is dead but, but she has not died' (Eleanor, p.50, line 1566).

This could suggest that Eleanor feels that although her co-twin is no longer alive, she has not stopped living, suggesting a presence of her is 'alive' and felt, or perhaps that part of the other is alive in the living, so if they are united, as depicted in subtheme 1.1, the dead co-twin will still live on in the living lone twin. This is also seen in the following excerpt:

'MP is dead..but, not gone..that is the word

(Mhm)

not gone, and she never will and I know she will not, she will be right by me all the way' (Eleanor, p.49, lines 1554-1556).

Confidence was expressed in her tone and she presents the feeling of the presence of her sister as almost like a fact.

These extracts differ from traditional ideas about grief stemming from Freud's (1917) work on mourning, leading to the 'grief work' concept in which the aim for the bereaved was to sever attachment to the deceased. However more recently, in the 1990s, a paradigm shift led to the emergence of a continuing-bonds perspective (Klass, Silverman & Nickman, 1996).

Jane spoke about the presence of the co-twin specifically in relation to therapeutic work with lone twins, stating that the co-twin is present in the counselling room and that the practitioner has to work with this as well. Jane chooses strong words for this and there were hints of frustration in her tone - 'you have got to realise' – urging that practitioners must be aware of this and work with it, rather than fight it and push lone twin clients to move on without their co-twin, as she had found happening in some of her personal experiences of counselling. She reported feeling that in death twins remain twins, in the sense that the bond transcends death:

'you have got to realise I think when you are counselling a lone twin, you have got both of them in the room..and you know try as you might, to get the other one out you are not going to succeed, so you may as well just give in and, and work with it, really, you know' (Jane, p.23, lines 691-694).

Esther also depicted a continuing attachment to the deceased co-twin:

'You cannot..you cannot associate yourself with, with erm, I mean, if it is an ordinary sister..or even a husband to a certain extent, you know you can detach yourself a little bit. I mean, I am very happy..I mean, both my husbands were lovely and I was very happily married and I do not know what I would do without him, but I can..but with O erm, it was more..you, you cannot, it, it is happening to you really' (Esther, p.14, lines 433-437).

She expressed an inability to separate from her co-twin and that this was specific to that relationship. The notion of relinquishing ties to the deceased being the ideal

(Freud 1917) is a Western convention grounded in the traditional Western grief literature (Stroebe, Gergen, Gergen & Stroebe, 1992), but the twins in this study voiced that they do not need the separation in death, but rather that they need to move forward perhaps alongside or with their co-twin. This is seen in Rosendahl, Bülow and Björklund's (2013) study, in which they found that surviving twins, in telling the story of their loss, interpreted it as the memory of the deceased being kept alive, a continuation of the twin bond, and being able to move on with the co-twin. This also can be linked back to ideas about sense of self and identity, as narrative research posits that this story-telling serves as a source of self-representation (Bennett & Vidal-Hall, 2000).

Eleanor described the continuing bond in a similar manner, feeling she and her co-twin will forever remain a part of one another:

'Just that MP's still a part of me and always will be' (Eleanor, p.7, line 200).

Maria noted:

'I feel we are still whole in a way' (Maria, p.23, line 715).

As well as indicating the continuation of the bond, Maria's words also suggests that the sense of self is experienced as a 'whole' and can be related to subtheme 1.1, where twins noted they felt they were a part of each other.

Jane also described a continuing bond in a spiritual manner and noted the positives:

'I, it is kind of, it is like a spirit, it is kind of like dancing. She kind of like dances in my head..you know' (Jane, p.42, lines 1259-1260)

and

'We could just ping things off each other

(Mmm)

Which was fun

(Mmm, mhm)

But I kind of ping things off myself now

(Yes)

And I think it is her' (Jane, p.45, lines 1350-1356).

The metaphor Jane used suggests a connection on a mental level, for example 'bouncing' ideas off each other, and a cohesive and mutually beneficial relationship in some ways. Jane feels this idea transcends death, and so their relationship, including this part of it, continues. She also noted that she 'ping things off myself now', illustrating adaptability in the relationship but also noting that this bond continues: 'I think it is her', perhaps like a muse, suggesting that the relationship and bond

continue in a new or adapted form. Again, this depicts moving on with the co-twin, and contrasts with traditional Western views about grief resolution.

Mary described the continuing bond in the sense that she feels she has taken on a role her co-twin had, feeling she also in part became a mother to her twin sister's children:

'I am sort of aunty-mum' (Mary, p.18, lines 541-542).

Although not discussed, it might have been the case that Mary chose to fulfil this part-role, and some existing literature on co-twin loss has reported that lone twins often take on roles that the deceased had, as a way of keeping their co-twin alive or 'living for two' (Sandbank, 1999, p.197).

Jane's account documented the continuance of the bond in a slightly different manner:

'I am a twin, you know

(Yes)

And I am still a twin, and if you cannot understand that, you know, that is your loss really' (Jane, p.12, lines 353-355)

and

‘I am still, I still am very much a twin, you know, very much so but there is a lot of fears that come with that. You know like, when am I going to die? Is it going to be soon?’ (Jane, p.46, lines 1387-1389).

Jane talked about the continuing bond in terms of the continuance of the twin identity, noting she remains a twin. However for her, this also brings up fears about her own mortality and research suggests that co-twin death can affect survivor longevity (Tomassini, Alessandro, Skytthe & Christensen, 2002). This effect is greater in twins than in other siblings, and greater again for identical twins aged 50-70 (Tomassini et al., 2002), an age range similar to that of the present study.

As well as an apparent bond that continues with the deceased, there also seems to be a more purposeful and motivated or intentional attempt to maintain the life of the co-twin in some form, as seen in the next subtheme.

3.6.2 Subtheme 4.2: Trying to Keep the Co-Twin Alive

This subtheme captures what seem to be attempts at trying to keep the co-twin alive in some form, as a way of managing the loss.

Esther spoke about trying to be a grandmother instead of an aunty, which may have also been reinforced by others, although this is not clear:

‘you know her children..I mean, it was quite nice, I tried to be a, a grandmother to her children. Her little boy, you know, that is of O’s daughter, I went up to a..he was in a concert..

(Mhm)

and he was on the stage and he, he shouted out “Ooh look! There is my spare nan!” ’ (Esther, p.15, lines 463-466).

Alice’s account also documented trying to be the co-twin:

‘I sort of try to be her sometimes...though still being me’ (Alice, p.18, line 568).

This could indicate trying to keep her presence alive in some form. It also depicts a possible dilemma or conflict of the self, trying to be the other yet at the same time to be individual.

Jane said she had ‘bits’ of her twin scattered around:

‘I have got bits of M all over the place’ (Jane, p.17, line 501).

This could indicate a desire or need to keep her memory alive, not wanting to ‘let go’, by having or keeping things around that perhaps serve as reminders of her co-twin, or were her possessions.

Some participants also spoke about experiences of ‘seeing’ their co-twins. A desire to keep the co-twin alive could be behind this, which may be semiconscious or subconscious. Jill noted seeing her co-twin in her own reflection:

'I look in the glass and I see her but, but I just comfort myself that perhaps it is not best for me, but it is best for her' (Jill, p.12, line 374).

Esther noted similar experiences when looking at photographs of herself:

'Erm, but sometimes I think I see her and, I look at photographs of myself and, or, I catch myself in the mirror and I see E..in me..' (Esther, p.21, line 662).

Mary relayed a similar experience of seeing her co-twin in her own reflection:

'I look in the mirror sometimes [laughs] when I am in the bathroom – "Ooh, I look like D today" [laughs]. And um, I can see myself in her' (Mary, p.18, lines 541-542).

Mary interestingly said she can see herself in her twin rather than seeing her twin in herself, a particularly noteworthy phrase when she is the one still living and indeed the one looking in the mirror. This may also bring us back to the presence of an enmeshed sense of self that has been explored previously, although there is some contrast in what she says, noting that she looks like her co-twin, implying there is a presence of some separateness and/or difference.

Research shows that some bereaved people report 'seeing' the deceased, for example bereaved widows (Glick, Weiss & Parkes, 1974). This suggests that this in itself is not an experience unique to twins. However, with identical twins another dimension is present. The striking similarities in the way they look could create a very different sense to this 'seeing': it is, as Mary noted, like seeing the self within the other.

Another way of conceptualising these glimpses or ‘sightings’ of the deceased co-twin may be formulated around relocating the deceased within one’s life in some way (Rothaupt & Becker, 2007), which occurs across different types of loss (Worden, 2002). This leads the discussion to the fifth and final master theme exploring comparisons across different types of loss.

3.7 Master Theme 5: Grief Comparisons

The final master theme explores comparisons across diverse manifestations of loss and grief, and its subthemes refer to co-twin loss as being different from, and worse than, spousal or singleton sibling loss, indicating that co-twin loss could be considered a unique type of loss. The subthemes capture an essence of participants’ accounts, noting that participants feel the loss is different because of the nature of the twin relationship and bond.

3.7.1 Subtheme 5.1: Co-twin Loss as Different

Many participants described the loss of their co-twin as different from other kinds of bereavements. Eleanor compared it to spousal loss and described feeling a continuing presence of her co-twin but not of her husband:

‘and I know AB’s dead (husband)..and he is dead..but, MP is dead..but, not gone..that is the word’ (Eleanor, p.49, line 1554).

This is further illustrated by the following in Eleanor’s account:

‘MP has died but is still living’ (Eleanor, p.23, line 729).

Past bereavement research has shown that in conjugal bereavement, spouses do sometimes feel a sense of presence, which usually refers to a feeling of presence of the deceased, something that is difficult to pin down in terms of the known senses (Bennett & Bennett, 2000). However participant accounts in this study made a comparison with their spouses and noted the feeling being different. Some grief theories may help us understand this: Shuchter and Zisook (1993) noted identity changes occurring with loss, as the way we perceive ourselves and the world is altered. With spousal loss, the part of identity of being a couple has to change (Shuchter & Zisook, 1993). One might therefore suggest that a similar change could occur in co-twin relationships, and as Bryan (1995) noted, often this loss is greater than the loss of a spouse. Woodward (1998) attributes this to twins never having known what it is like not to be a twin, whereas spouses had their own, singleton identity prior to getting married and can re-marry and reinstate this bond. This can help us understand why twins in the current study may have felt differently about the loss of their co-twins and the loss of their spouses.

Esther spoke about the loss in comparison to both the loss of a spouse and the loss of a non-twin sibling. She also termed her non-twin sister as an 'ordinary sister', which could imply she feels something different and special in the twin-sibling relationship, the word 'ordinary' often being associated with mundanity. Esther described feeling unable to detach herself from her co-twin even in death, and that this was not the same for spousal or non-twin sibling loss:

'I mean, if it is an ordinary sister..or even a husband to a certain extent, you know you can detach yourself a little bit.' (Esther, p.14, lines 433-435).

Maria highlighted that the twin relationship is different because of twins being together since birth, and she also compared it to her relationships with her non-twin siblings, possibly suggesting a closer bond between twins than non-twin siblings:

'but this is different because, but and I say you, people think well you have lost your sister, but, a twin sister is different because she has been with you ever since you know, the moment you are born' (Maria, p.20, lines 618-619).

It would have been interesting to explore why being with your twin-sibling since the moment of birth made the loss different for Maria, from for example the loss of non-twin siblings, particularly if those siblings were older and could therefore have been present from birth, albeit in a different way. This raises questions about being present together and about the relationship in utero.

Jack also described co-twin loss as different from other losses:

'It, it, it, it was, it was an awful experience. Er, losing a twin

(Mm)

is different to losing somebody else' (Jack, p.21, lines 643-645).

Jack's account used the terms 'awful' and 'different', which suggests he feels it is different in a more negative way and that it felt worse than others kinds of losses he had experienced.

Jack also provided a striking image, describing being at his co-twin's funeral as like seeing what his own funeral would look like:

'Um, I remember when I went to his funeral, to the cremation

(Mhm)

And er, I saw his cas-, casket, being, rolled er, wheeled passed me with the flowers on it and I had what I can only describe as an out-of-body experience

(Mhm)

I felt that was me!...I felt I was looking at myself, I felt that I was, I was, having a preview of my own funeral, because one day that will be me!' (Jack, p.14-15, lines 445-451).

One might infer that this may be experienced as being different from experiencing other kinds of losses and attending other funerals. Although when someone dies, thoughts about our own mortality become more conscious (Lageman, 1986), Jack's account may suggest that this occurs in a different manner for identical twins. This is seen in his description of having a 'preview of my own funeral', and also indicated in his tone which depicts his shock at the experience. One could infer that this does not occur with losses of others, as we do not directly, physically resemble each other in the same way. The fact that Jack described this as an 'out-of-body experience'

perhaps also highlights a spiritual, paranormal or supernatural experience on some level.

Participants' descriptions under this theme capture the differences felt in their experiences of the loss of their co-twins compared to other types of losses, particularly spouses and non-twin siblings. The next subtheme explores further the ways in which this is different.

3.7.2 Subtheme 5.2: Co-twin Loss as Worse than Spousal and Sibling Loss

The final subtheme examines the suggestion that co-twin loss is worse than other kinds of loss. Sarah illustrated this in her account in the following excerpt:

'and it was a very different death to when my husband died..very very different

(In what ways was it different?)

It was, a hundred times worse, a hundred times worse and that is probably a horrible thing to say but it was, because I was so close to C and I had only known, my late husband for five or six years..yes five or six years, so when you think you have got all that history, with someone that is well she was there all my life with me, it was a lot worse, a lot worse' (Sarah, p.18, lines 542-548).

Sarah attributed feeling the loss of her co-twin as worse than the loss of her husband to the fact that she had known her co-twin for her entire life. The term 'history' indicates a multitude of shared experiences that connect her to her twin over a more

extended period of time. The phrase ‘there with me all my life’ also indicates the shared nature of their experience and lives, although it may also be attributable to the fact that she had known her late husband for a considerably shorter time-period.

Repetition of the words ‘very different’ and also ‘very’ in its own right emphasises Sarah’s attempt to show that the loss of the co-twin is incomparable to that of a spouse. The repetition of the phrases ‘a hundred times worse’ and ‘a lot worse’ demonstrates the intensity of the loss. Sarah noted that stating that the loss of her co-twin is much worse than the loss of her spouse is a ‘horrible thing to say but it was’, suggesting she feels some conflict or guilt around saying this and feeling this way.

Sarah’s repetition of the phrase ‘a lot worse’ suggests that the grief felt for the co-twin was experienced as harder and perhaps experienced more intensely and with more negative effect, compared to the loss of her spouse. The social bond between identical twins has been described as among the closest and most enduring of human social relationships, and evidence for this conclusion comes from a comprehensive body of clinical, observational, experimental and biographical data (Segal et al., 1995). Segal and Bouchard (1993) and Segal et al. (1995) found that twins also grieve more intensely for deceased co-twins than they do for deceased non-twin relatives and this is in line with what is seen with Sarah here. Although only this direct quotation explicitly depicts co-twin loss as worse than other losses, the data seems to lean towards co-twin loss being a unique experience that sets it apart from other bereavements, as depicted overall across of all the themes presented.

It is also seen in the following example:

'but with adult loss..I reckon, with adult identical loss, I reckon it is the total worst..

(Mhm)

Because they have been around longer, um..and you are closer' (Jane, p.14, lines 405-407).

Like Sarah, Jane links to the length of time twins have been around each other, indicating again that this sense of a harsher loss is due to the co-twin having being present for the whole of the bereaved's life.

As well as this, the uniqueness of the nature of the twin relationship itself might be considered, which could perhaps predispose one to experience the grief in a particular way compared with, for example, general sibling loss or spousal loss.

This final subtheme of co-twin loss being considered by participants as 'worse' than non-twin sibling and spousal loss, suggests that participants may feel that a hierarchy of grief exists, in which co-twin loss is felt to be the worst kind of loss that one might experience. Some literature documents that kinship plays a role in such a hierarchy (e.g. Robson & Walter, 2013), for example, that partners and children of the deceased experience loss as worse than a sibling of the deceased (Doka, 1989). However, identical co-twin siblings share 100% of their genetic information (Bryan, 1983) so this challenges the above example. Marris' (1986) ideas about hierarchies of loss are

also relevant in terms of his ideas about hierarchies of social roles, noting for example that the mother who loses their only child also loses the role of ‘mother’ too, or at least temporarily for some. This could be linked back to ideas documented earlier in this chapter, that the twinship can never be reinstated (Woodward, 1998) and perhaps this may affect the loss experience. Considering that every loss experience is unique (Doka, 2016) whilst some participant accounts have expressed co-twin loss as the worst type of loss they have experienced and feel they will ever experience, this thesis does not make claims that this is a worse type of loss, although it may seem to be experienced differently in some respects to others types of loss. Grief is highly unique and therefore this research adopts the position that grief experiences are distinctive, individualistic and incomparable in many ways. If one adopted the idea of grief hierarchies, this would have implications for practice and people may feel judged and not understood if we were to rank grief experiences in a hierarchical manner.

3.8 Reflexivity

Reflexivity in the research process has been described as ‘self-awareness and agency within that self-awareness’ (Rennie, 2004, p.183). It is the process that provides opportunity for the researcher to reflect on and try to understand how the researcher’s own experiences affect the research (Morrow, 2005). My world-view and the way I have interacted with the participants will have influenced the data collection and analysis as there is no such thing as a ‘view from nowhere’ (Biggerstaff & Thompson, 2008, p.221). The analysis is in this way the researcher’s interpretation of the participant’s attempted sense-making of the experience (Smith, 2011).

At the start of the data analysis process I doubted the quality of the data and felt nothing novel was emerging. During this time I also struggled to find a balance between keeping in mind the need to stay close to and ground initial themes in the transcripts, yet simultaneously access interpretative levels in order to begin generating themes. Each revisit to the transcripts gave rise to new insights and further engagement with the data over a number of months; stepping away from it and revisiting meant I found that novel and interesting ideas did emerge. However, it can be seen that there is not a quote from each participant under each subtheme. It became apparent as themes emerged and were grouped, and others discarded, that the novel ideas that did emerge and were therefore important did not arise for all participants.

The subtheme around twins feeling they were a part of each other within their twin relationship is demonstrated by extracts from two participants. Although not all participants have extracts within this, it is an important subtheme as it sets the context for participants' accounts of bereavement. I felt it was an important subtheme for another reason: because the general population does not seem to feel the same depth of connection that twins describe feeling. Within the 'embodiment of separation' subtheme, again three participants expressed some form of this experience. Although this is a small number, I felt the theme was particularly striking and should therefore be included since something novel seemed to be emerging. Embodiment of the separation was depicted further in the violence subtheme, entailing more participant accounts. Violence within the embodiment of the separation was given a subtheme in its own right because of the power of the metaphors relating to violence that were present. The divided

self also involved fewer than half of the participants but was felt to be important because within it, conflict arose, and because for some it also related to previous subthemes, particularly feeling a part of each other in life and therefore feeling a division in death. Continuing bonds are represented by half of the sample and were included because despite continuing bonds being found in other types of bereavement, they manifested in a unique way for twins. A related subtheme followed although again represented by only half of the participants, because a novel idea emerged of a more intentional continuing bond which has not been found in existing literature. Lastly, grief comparisons were made a master theme as over half of the sample spoke about these, and they are a key idea to consider if co-twin loss is a unique experience that differs from other types of bereavements. Although within this master theme the subtheme of co-twin loss as worse than sibling or spousal loss is documented in extracts from only two participants, this was included as a subtheme as it helps us understand how twins who have experienced different losses feel, something we can only obtain from twins themselves, who here also provide reasoning for their feelings.

Other general reasons for having quotations from fewer participants in some subthemes include the need at times for further probing, as explored previously. One must also note that from the ten interviews that were conducted, no material was used from Mariah's interview. This was because it was felt that the novel insights were not emerging from this interview transcript. This could be due to a number of reasons, including for example the nature of the research topic and poor interviewing technique, as discussed previously. On finalising the themes it became apparent that extracts from Mariah's interview were not relevant in

terms of the ‘novel insights’, I felt what was emerging were grief reactions that are expected and common to the general population, for example shock and denial (e.g. Kübler-Ross & Kessler, 2005) and therefore nothing from this transcript was used in the final results. However on reflection, a negative case analysis could have been explored, as this allows for one’s initial assumptions and themes to be challenged and modified (Henwood and Pidgeon, 1992).

I found the apparent violent dimension to embodied grief most striking. Although I termed ideas in participant descriptions as ‘violence’, the concept was explored broadly and an overview of accessible grief literature among different relationships to the deceased revealed that this idea was sparse and where it was documented, it manifested in a different manner. Notably, in the current study participant accounts documented still experiencing violent pain years after loss, whereas this was only in the ‘immediate aftermath’ of the death in one study, which made reference to parental loss of a child (Gudmundsdottir, 2009, p.260).

I also chose to have one broad research question and no sub-questions. Whilst I anticipated that within descriptions of what the twin relationship was like material such as feeling connected to each other might arise, as this is documented in existing literature, I did not want to assume this and its importance, and so instead I chose to see what arose. As a result, I kept the research question broad; exploring what the loss experience was like. This consequently already had the potential to lead to vast accounts and I felt adding

further sub-questions could lead to an unmanageable sized project for a doctoral scaled piece of research.

3.9 Analysis Summary

The analysis has sought to present themes focussing on what the twin relationship was like, to set the context for the accounts of co-twin loss, the experience of the loss, how the loss was managed and a comparison of co-twin loss with other types of bereavement.

The first master theme captured experiences of the twin relationship in which an enmeshed sense of self was prominent. Twins also felt that a unit identity was reinforced by others around them. The second master theme focussed on embodiment, which spanned the twin relationship and was also seen within the loss experience. Perhaps, since embodiment experiences are so prevalent in twin relationships, there is a natural inclination for grief also to manifest physically in the event of twin loss.

The third master theme documented the ways in which the separation was felt emotionally. The fourth master theme focussed on the management of the loss, which was seen in the different ways the relationship with the deceased was continued. The fifth and final master theme explored co-twin loss as compared to other kinds of bereavements, in which it was seen that co-twin loss seems to be a unique type of loss, and was described as the worst kind of loss that might be experienced. Finally, an overarching thread throughout the themes is embodiment, which appears to run throughout the twin relationship pre and post loss and within the loss experience itself.

Chapter Four: Discussion

4.1 Overview

This chapter explores themes generated in the study in relation to relevant existing literature, but it will also draw upon additional literature, reflecting the inductive nature of IPA, a method that moves the researcher to ‘new and unanticipated territory’ (Smith et al., 2009, p.113).

Semi-structured interviews were conducted with nine female participants and one male participant, all of whom volunteered to take part in the study. An interview schedule was designed to address the following: how is loss of an identical co-twin in older adulthood experienced by the surviving identical twin? A summary of the findings in relation to previous research forms the first part of this chapter.

Implications for practice are also explored and reflexivity is documented in grey font. Limitations of the current study are then considered, and lastly, the chapter comes to a close with proposals for possible directions for future research.

4.2 Summary of Findings

The emergent themes in this research suggest that the nature of the twin relationship sets the context for how co-twin loss is experienced and managed, and how it compares to other kinds of losses.

The main ideas that have emerged from the analysis are supported by existing literature, such as twins feeling connected, embodied grief and continuing bonds with the deceased. However, the current study expands on these themes, adding new

insights across different dimensions. These new insights include a unified sense of self that may affect how the loss, sense of self and identity are experienced, shift or change; a violent embodied dimension to the loss; a continuing bond with the deceased that takes different forms from those arising with other losses; and the idea that co-twin loss is unique. Furthermore there is an overarching thread, throughout the results, of embodied experience of attachment, which will be examined further. The discussion will continue to explore these concepts one-by-one in relation to existing and supporting literature.

4.3 Understanding the Emergent Themes in the Context of Existing Literature

Here we explore the representation of the emergent themes in the existing literature, and how the themes as illustrated in this study expand upon what has already been documented in the past.

4.3.1 The Twin Relationship

The first subthemes of *'You are a part of each other'* and *'We were always just called "Twinny"'* captured a sense of being connected and united as a pair. This was talked about in the sense of being connected in an emotional way, feeling that the twins were a 'part' of each other and that two together made a 'whole'. This is something that has been documented in existing literature. These findings could be argued to support Schave and Ciriello's (1983) ideas about the attachment between twins and the ways in which twins can sometimes attach to each other more than to the primary caregiver (Akerman & Suurveen, 2003), resulting in an interdependent relationship. This last observation could also indicate that twins feel a part of each other, as in development, singleton children must separate and individuate from the primary caregiver (Mahler,

Pine & Bergman, 1975) whereas twins have the extra task of separating and individuating from the co-twin as well from the primary caregiver (e.g. Langers & Norden, 1978; Akerman & Suurvee, 2003). This also supports Siemon's (1980, p.389) ideas about a 'twinning reaction' and a fusion of the self and the co-twin. The findings also concur with Macdonald's (2002) study of the experiences of twinship and how MZ twins often feel viewed as a unit, so that when one dies, the other feels no longer whole.

Reference by others to twins as 'Twinny' or as a pair or whole meant that twins in the study felt others perceived them this way. This reinforces a joined sense of self and being, that they are two parts that together make up one whole set. The social reinforcement of the twin identity has been documented; Siemon (1980, p.388), for example, noted that 'societal expectations' and reactions from others reinforce the idea of twins being a unit. The current study is in this way aligned with existing ideas about twins' sense of self and the ways in which this can indeed be entwined with that of the co-twin.

Effects of bereavement on identity are seen in general in the bereavement literature (e.g. Parkes & Prigerson, 2013), but it seems that the sense of identity is different in twins, and so the impacts of bereavement on identity will also be experienced differently. Schave and Ciriello (1983) found that many twins define themselves in relation to the co-twin, and this was seen in the current study where participants' accounts documented that they felt they were a part of each other on different levels including emotional, spiritual and even physical. On the basis of this, it could be

suggested that ideas of embodiment can be usefully drawn upon to explore these ideas further.

4.3.2 Embodiment

One of the most striking elements of the results was a strong sense of attachment and grief being felt within the body. This could be described as ‘embodiment’.

Embodiment in this study is referred to as our thoughts, feelings and behaviours being grounded in our sensory experience and our different bodily states (Meier, Schnall, Schwartz & Barghd, 2012). Existing literature has documented that social processes also influence one’s sense of self and embodied experience (e.g. Crossley, 2006), a finding that chimes with the ideas above about the sense of self and reinforcement of this by others. Furthermore, embodied experience has been argued to be central to meaning-making, particularly through metaphors (Gallese & Lakoff, 2005) and particularly for meaning-making in bereavement (e.g. Gudmundsdottir, 2009), and this has emerged across a range of relationships. It is seen for example in bereaved parents who lose a child (e.g. Gudmundsdottir, 2009).

In the existing literature, it seems that embodiment in relation to twins had previously only been explored in conjoined twins in the sense of their physical joining (Prainsack & Spector, 2006). The experience of embodiment in and that of identical twins has seemingly been overlooked (Prainsack & Spector, 2006). Embodiment was documented in the current study within the twin relationship in subtheme 2.1, where participants’ accounts described co-twins feeling a part of each other on different levels. One level included having a physical, biological connection to each other, as identical twins share all of their genes (Bryan, 1983). Some twins in the current study

described feeling that this biological connection was almost like a precursor for their knowing what the other was feeling and thinking. For example, Esther and Jack noted that they felt the genetic link shared with the co-twin meant that they knew what the other was thinking and feeling. Ideas and connections such as these are difficult to measure, and as a result, experiences of this sort that have been documented are based on anecdotal evidence (Playfair, 1999). Furthermore, Jack (*p.21, lines 647-656*) also spoke about this notion by referring to the origins of identical twins descending from a single egg that splits, which he documented as important for him, attributing this as a causal factor for an emotional connection between identical twins. Conducting qualitative research has allowed for participants to freely express their experiences, which enables us to capture feelings and ideas that might not be obtained in a quantitative manner.

In the existing grief literature, grief experienced in an embodied way has been seen in groups such as bereaved parents when a child is lost, where the loss has been described as a loss of a part of the self (Klass, 1988). This is also seen in conjugal relationships (Klass, Silverman & Nickman, 1996), but in relation to and resulting from unification in marriage or a committed relationship prior to loss (Woodward, 1988). The current research departs from these ideas, by documenting that twins in the study described this embodied attachment as lasting throughout the life-course prior to the loss, whereas before couples have come together and known each other, there is no known or felt attachment and each member of the couple exists as an individual leading a separate life. Perhaps due to the embodied attachment predating the loss in the case of twins, this form of attachment continued after the loss in a more profound way for the participants of this study. The participants here were also raised

together with their twin, and this perhaps also contributed to their having experienced an embodied attachment for longer.

Two participants also spoke about embodiment within the twin relationship in terms of feeling the others pain. This is documented by anecdotal evidence in the literature (Playfair, 1999). A sympathetic twin bond is also documented cross-culturally, for example in the Yuma tribe in North America (Pector, 2002). Apart from Couvade Syndrome, which has no clear physiological basis and so is often dismissed medically (Klein, 1991b), this type of sympathetic bond seems, on the basis of existing literature, to be unique to twins.

This could therefore indicate that the attachment relationship between twins is different from that in any other relationship. Although it could be argued that the mother and baby in the womb also share an embodied attachment and genetic link, these are different from those between twins. MZ twins share a different genetic link again, by sharing 100% of their genes (Bryan, 1983), and they are also the same age (Preedy, 1999) and at the same developmental stage (Mogford-Bevan, 1999).

What also stood out in the current study was a dimension of violence in embodied grief. Embodied pain has been documented in grief, for example through descriptions of notions of amputation, shattering or something being missing (Klass & Marwit, 1988-89). However in the results in this study there was a dimension to grief that conveyed a sense of violence within the pain felt, which continued after the death. The existing literature also contains one study in which grief was found to be embodied and described in a violent manner in terms of the 'body as mutilated', but

this pain ‘only lasted a short while’ ‘in the immediate aftermath’ of the loss (Gudmundsdottir, 2009, p.260). This perhaps suggests that violent pain that continues for years after the loss may be unique to the MZ twin population and may indicate a greater depth and intensity to the pain of the loss. In the current study elements of violence were seen in metaphors of how the loss was managed in the body generally, where participants described sensations of being cut and ripped in half and being pulled apart, and that part of the self is lost or has died. Metaphor use in bereavement has been documented as common, and aids the bereaved in expressing their grief (Umphrey and Cacciatore, 2014).

In this study embodiment can also be linked to identity, because if remaining twins saw themselves as a unified whole self through being connected to the co-twin as Siemon (1980) and Macdonald (2002) suggest, in death they may not feel whole, possibly affecting how they see themselves. This idea of no longer being a whole was seen in many participants’ comments, as already discussed, for example they described feeling as if a part or half of the self were gone, or feeling ‘cut in half’ or ‘pulled apart’. Participant Jane (*p.12, lines 342-345*) also made direct reference to identity change with the loss, noting that she felt she had lost her identity and did not know who she was. This can also be linked back to ideas about the fluidity of identity and the view that identity shifts with different experiences and threats (Breakwell, 1986). The alignment of the findings with this theory posits a need for assimilation and accommodation of the loss experience into identity, so that adjustment to the loss can occur (Jaspal & Breakwell, 2015). More specifically for twins in this study, this adjustment could be thought about as finding a new way of being and learning to live

as one, as most often participants described feelings of being connected and being a part of each other on different levels, indicating an enmeshed sense of identity.

4.3.3 Continuing Bonds

Although continuing bonds are found across other relationship losses such as parent-child relationships, conjugal relationships and sibling relationships (Klass, Silverman & Nickman, 1996), what was interesting in the current study was that these bonds are considered to be continued within the living lone twin, or the surviving twin feels a need to move on alongside the deceased co-twin and that the twin bond transcends death. The latter was seen, for example, in Jane's account (*p.23, lines 691-694*) where she noted that she was 'still a twin'. Participants' accounts suggested that the twins continued to remain a part of each other even after the physical death, including on a mental level, in self-identity and on a spiritual level. The findings therefore also differ from classic psychoanalytic theory, the ideas of which were primarily drawn from Freud's (1917) work on detachment from the deceased, and from stage theories of grief, which also recommend letting go of this attachment to the deceased (e.g. Bowlby & Parkes, 1970). Furthermore, Jane's account emphasised the importance of working therapeutically with this bond and identity, which she feels remains with her.

The findings also support research that documents continuing bonds with the deceased being beneficial (Klass, Silverman & Nickman, 1996). In this study, Jane (*p.45, lines 1350-1356*) spoke about a presence of her sister in a positive way as something that continued to inspire her and connect with her when she thought about things. This study has also shown that there seems to be an intentional desire to keep the deceased alive in some form. This may also be thought of as keeping that part of

the self alive, if co-twins feel and are connected as described in the initial themes in the analysis.

A further unique dimension within this apparent need to keep the co-twin alive is the fact that MZ twins have a close physical resemblance, which sparks a range of feelings and adds an additional dimension that is exclusive to them: their 'sightings' of the deceased are unique because of this. Perhaps this can also be thought about in relation to twins sometimes trying to maintain a sense of duality as a form of denying the separation (Siemon, 1980). It could also be conceptualised as keeping a part of their own identity and self alive.

Preservation of the deceased co-twin is documented cross-culturally, for example in the Yoruba tribe in Nigeria where tradition relates that the surviving twin must carry the *ere ibeji* – a wooden carving of the deceased - to preserve the twin identity and appease the deceased's spirit (McIlroy, 2012). This shows that there is even contrast in the expression of co-twin loss across different cultures. It seems that nothing is documented in the accessible literature about formally 'preserving' the co-twin in a similar manner in Western culture, but that by contrast 'separateness predominates in Western cultures' (Silverman & Klass, 1996, p.15). This perhaps could be linked to Western cultures' general emphasis on individuality (Silverman & Klass, 1996). This is in turn relevant for the seemingly enmeshed sense of identity between twins apparent in this study, seen in master theme one and the existing literature (e.g. Siemon, 1980; Macdonald, 2002). Prevailing ideas today about emphasising the importance of separation and individuation from a co-twin (Klein, 2003a) can be set alongside the examples here of twins attaching to each other and having difficulty

forming a separate sense of self (Akerman & Suurveen, 2003). However, perhaps what is key and important to remember is that ‘The grieving process is embedded in cultural traditions’ (Silverman & Klass, 1996, p.40) and this seems to be exactly what is seen here. This contrast of grief in co-twin loss in different cultures reinforces the next concept of co-twin loss as a unique experience.

4.3.4 Co-twin Loss as a Unique Experience

The few studies that exist that have explored co-twin loss have mainly been quantitative in nature. Some participants in the current study made comparisons across grief experiences and described co-twin loss as a unique loss in the sense that they felt it was different from and worse than other kinds of losses, particularly spousal and non-twin sibling loss. Some participants could articulate how it was different, noting it was because the nature of the bond with the co-twin was different, and some also attributed this to their biological, as well as emotional, connectedness.

A finding that co-twin loss seems to be a worse type of loss than that in other sorts of relationships would perhaps support Segal and Ream’s (1998) and Woodward’s (1988) findings of increased grief intensity in co-twin bereavement, and Siemon’s (1980, p.398) statement of co-twin loss as ‘more traumatic’. This was seen in the current study where one participant made direct reference to and comparison of this, saying co-twin loss was ‘one hundred times’ worse than spousal loss. This could indicate that the loss of the co-twin is felt as more intense. Furthermore, comparisons between co-twin loss and other familial losses have shown consistently that twins, and in particular MZ twins, fear and grieve the loss of their co-twin more (e.g. Segal & Bouchard, 1993; Segal et al., 1995).

The current study also supports both of these findings in a different way because of its qualitative nature, through which it extends existing findings by providing some of the ideas and some of the reasoning that twins in the study felt lie behind the experience.

4.3.5 Summary

Four main areas have arisen in the discussion that are related to themes that emerged in the analysis. The first was a sense of being entwined with the co-twin in different ways. This was followed by a sense of embodiment that spanned the twin relationship in life and in the experience and management of the loss. A third main area was that of continuing bonds with the deceased. Within this, what was novel was the way in which this seemed to be a necessity on different levels, one of these possibly relating to identity and sense of self, for example keeping a part of the self ‘alive’. Lastly, co-twin loss is shown to be seemingly a unique experience in a number of ways, including that it was reported as different from and worse than spousal and non-twin sibling loss. It also seems, relating back to the other themes, that it is because the twin relationship appears to be different from other relationships, along different dimensions, that the loss also manifests and is experienced differently.

4.4 Clinical Implications

The results from this study seem to inform us that there is a link between how the twin relationship is experienced and how the loss is felt, manifests and is managed. For example, the embodiment of attachment emerges in subtheme 2.1 where descriptions centre on feeling ‘a part of each other’ and on physical connectedness. This finding may also lead us to suggest that in clinical practice and when counselling

lone twins, one may first need an understanding and processing of the twin relationship prior to the loss as well as currently. Exploring whether lone twin clients feel their relationship predisposes them to experience the loss in a particular way may also be helpful, as this could help normalise their feelings. Research literature has documented how allowing the bereaved to tell the ‘story’ of their loss not only keeps the deceased ‘alive’ and represents a continuing bond (Rosendahl, Bülow & Björklund, 2013), but also aids in preserving self-identity (Bennett & Vidal-Hall, 2000). This could be applied to therapeutic work with co-twin loss survivors, as the results of this study have shown an apparent need for some to ‘keep’ the co-twin ‘alive’, which could in turn be linked to the survivor’s sense of identity. It follows that if an entwined identity had ensued in life, ‘keeping’ the other ‘alive’ after death may be linked to keeping a part of the self ‘alive’, and so also act as an aid in preserving self-identity.

Many participants talked about still ‘being’ a twin, and about the presence of the co-twin in various senses, not only in terms of identity and self, but also in a physical, embodied sense and a spiritual manner. Jane (*p.23, lines 691-694*) also made direct reference to counselling the lone twin, reporting that she felt both twins, i.e. the deceased included, are present in the counselling room and that both need to be worked with.

Identity is also something to be considered in clinical practice. The entwined identity that seems to be present among twins may mean that, when counselling bereaved twins who have lost their co-twin, it might be useful to focus on helping the client learn what is self within the fusion of self and co-twin, to develop an individual sense

of self, and so to grow as an individual. Indeed, as Siemon (1980) has suggested, this approach could be helped by recognition and tolerance of the loss, and by the development of a self-image in which the person does not have to be part of a whole.

The current research differs from traditional, Western ideas about grief, and explores a continuing bonds perspective in a different way. On the basis of the findings and participants' accounts, it could be suggested that participants felt they needed to move forward with, or alongside their co-twin, rather than detaching from the co-twin when death occurred. Perhaps this means that practitioners need to find a way of helping twinless twins to move forward in some way by which identity evolves into an adapted form, for example by living with the co-twin in a different and/or modified form, re-integrating this into the self and the surviving twin's experiences, and finding a way to be. This idea is supported in the existing literature, for example the exploration by Malkinson, Rubin and Witztum (2006) of a reworking of bonds with the deceased as an important focus for therapy.

Counselling Psychologists need to be mindful of theory and how this influences practice, as theories may unthinkingly and implicitly be applied to, or drawn upon in relation to, all clients. Theory can be very powerful and there is a need to remember to remain true to Counselling Psychology and the importance of individuality and subjective experience within it (Strawbridge & Woolfe, 2010). This involves being mindful of our own assumptions and striving to see things from the individual's personal perspective. The specific skill sets that Counselling Psychologists have do help with this, but a balance must also be struck between these and theory that is used to inform practice.

Another implication for practice may be the need for education for practitioners about twin relationships and how the resulting loss may manifest. It seems logical that only by having an understanding of co-twin relationships and what the co-twin loss experience is like, can we attempt to help our lone twin clients. This education could also be extended to the families of bereaved co-twins, helping them to understand what the remaining twin is uniquely going through (Pector, 2002).

Existing research has shown that facilitating clients to reflect on how the loss experience has affected them using narrative exercises, and promoting dialogue with the deceased, for example in the form of letters, can also help the bereaved by promoting integration of the loss into their lives (Neimeyer, 1999). Lastly, so that twins feel better understood, acknowledgement that co-twin loss feels worse than all other kinds of loss is also something to be considered.

4.5 Critique of the Research

Some interesting findings have been found in this study; however it is important to note that these findings are dependent on the design. Before any final conclusions are drawn, the limitations of the study need further exploration and consideration.

It must be noted that this study is based on the experience of ten participants and it is not argued that they are necessarily representative. Rather one must consider the demographics of the participants and the impact of these, for example all participants classed themselves ethnically as White-British. Future research may look at other ethnicities and explore how the experience of people compares across different

ethnicities, particularly as people grieve differently in different cultures (Rosenblatt, 2001).

IPA involves using small sample sizes and sometimes IPA studies are criticised for this (Pringle, Drummond, McLafferty & Hendry, 2011). However in this IPA study ten participants were recruited which is considered somewhat large for qualitative research and IPA. Furthermore, the aim of IPA is not so much generalisability but ‘theoretical transferability’ (Smith et al., 2009, p.4). IPA studies are more interested in gaining a detailed initial insight within a few particular cases, and if other studies then build upon this, claims can gradually be made more generally (Smith et al., 2009). This participant group was anticipated to be a hard-to-reach group and this was seen during recruitment, where recruitment criteria had to be broadened. For example, age at loss and current age criteria was widened. However, this movement allowed for a good sample size for an IPA study to be obtained.

As mentioned above, there were some difficulties with obtaining the sample. Current age ranged from fifty-eight to ninety, the age at loss ranged from fifty-one to eighty-four, and the number of years since loss ranged from two to ten years. Ranges for all of these factors had to be wider than originally set out, in order to obtain participants. It may be argued that the differences could create a different picture in the results; so for example losing someone ten years ago rather than two could mean that the loss may be felt as less intense or may have been more successfully adjusted to. Furthermore, given ideas on identity as socially constructed (Gergen & Gergen, 1988), the experiences of identity may differ with the historical context of a person’s upbringing and time of loss. Having said this, Jane, whose loss occurred ten years

ago, spoke about pain still felt in violent ways so perhaps the factor of the amount of time since loss does not have an impact for twins. Further work might control better for this so that the impact of such factors can be seen. Although the study was hoping to focus on loss in older adulthood, and had defined this as sixty-five years old and above using the World Health Organisation's (n.d.) definition of older adulthood in Western society, in the end some of the people who volunteered for the study were younger and some had lost their twin at a younger age. All participants described the loss of their co-twins to illness and all were raised together in childhood. These also help us think more specifically about how the loss of an identical co-twin in mid to later life by illness is experienced. However, the type of illness that co-twins died from differed, and this could impact the results. For example different illnesses could have different effects on the surviving twin: observing the co-twin experiencing Alzheimer's disease, for example, could be quite traumatic if the sufferer experiences memory loss, mood swings and disorientation symptoms (NHS Choices, 2016), while the experience of observing loss from heart failure could be quite different.

The study used different modes of interviewing, including face-to-face, telephone and one Skype video-call interview. This was appropriate for a number of reasons. With sensitive topics some participants prefer telephone interviews as these provide some anonymity within the interaction (Fenig & Levay, 1993) and are perceived by the participants as doing so (Greenfield, Midanik & Rogers, 2000). The option of a telephone interview also allows one to obtain data from those reluctant to participate in face-to-face interviews (Tausig & Freeman, 1988). It was also a cost-effective method of data collection (e.g. Miller, 1995), as some participants' geographical location was far away from my own and travelling expenses and overnight

accommodation was expensive (for example between London and a location near Scotland). What is more, some participants could not travel because of poor physical health, and others did not want to travel, while many did not want to be visited in their homes.

However one also needs to consider that in telephone interviews it is not possible to perceive non-verbal communication (Creswell, 1998) such as visual cues (Miller, 1995), although verbal cues such as hesitations and sighs can still be picked up and followed up on (Sturges & Hanrahan, 2004). One participant was interviewed by Skype video-calling, which was preferred over telephone interviews because it allowed for nonverbal communication to be picked up on even though both parties were not present in the same room. Skype video-calling might have offered a workable compromise for difficult-to-reach participants, but the sample consisted mainly of older adults, many of whom did not have internet access. There was also a researcher personal preference for face-to-face interviews. The researcher's other role as a Counselling Psychology clinician means that there is a natural preference for these, as it is often felt that rapport development is stronger in this situation, but some research argues that an equally good rapport can be developed through other communication modes (e.g. Sturges & Hanrahan, 2004). Furthermore, the interviews in this research were not therapy, which is a different type of interaction altogether. Instead one may argue, as Miller (1995, p.73) does, that 'telephone interviews are not better or worse than those conducted face-to-face', but that telephone interviews are effective for gathering sensitive data (e.g. Babbie, 1986, Tausig & Freeman, 1988) even when compared to direct questioning (Weissman, Steer & Lipton, 1987).

The findings of the research also need to be considered in terms of the position of the researcher and the impact of this on the process of data collection and analysis. This is considered below, together with a critique of the interview schedule.

4.6 Reflexivity

Regarding the interview schedule, the research aimed to keep the opening question as broad and as open as possible, as suggested by Smith, Flowers and Larkin (2009). However it was found that this question perhaps yielded too much focus on what the deceased co-twin was like, at the expense of the latter part of the question - what actually happened in the loss and that perhaps this made it harder to keep participants focussed on the loss itself later in the interview. Perhaps the use of words such as 'death' and 'died' rather than 'loss' could have helped this focus too. I found that I had chosen words such as 'loss', which I also noticed in my clinical practice when working with bereavement alongside conducting the research interviews. I have reflected on this and concluded that I feel it is more sensitive to the person and a 'softer' term, and perhaps has a more empathetic feel. This could also relate to my perception of the fragility of bereaved people. Furthermore, it may also form part of a fear of not wanting to be perceived as insensitive or too firm. I was also aware of cultural differences, particularly personally coming from a mixed-race background, and of how loss is viewed and grief is expressed differently in different cultures (Rosenblatt, 1993); it is still largely something that we 'sweep..under the carpet' in Western cultures (Parkes, Laungani & Young, 2015, p.4). I think that if I had used the word 'death' perhaps this would have helped participants to focus in more depth on what their personal experiences of their loss were like.

Another aspect to consider is the nature of the research topic. Grief is a difficult topic and participants may have experienced ambivalent feelings, for example wanting to explore their experiences but during the interview process moving away from the direct subject matter, perhaps due to the pain that can arise with bereavement. Perhaps this movement itself may also be conceptualised as a defence mechanism.

As well as this, at times during the interviewing process there was some defeatism and/or a feeling of wanting to get the interviews done quickly in order to be able to continue with the rest of the research process, perhaps at the expense of quality. At times I felt some participants were telling stories that I felt detracted from the focus of their personal experiences of loss. Having clinical experience of working with older adults, I had found it quite challenging and felt that perhaps this group might take a bit longer to develop rapport and trust in this context, which posed a challenge for the research interviews, which were one-off meetings. In addition, some were conducted by telephone, which perhaps made the difficulty even more challenging.

With hindsight, time-permitting, I ideally would have waited to be able to recruit a sample where all participants consented to being interviewed face-to-face. This is because I personally feel that rapport development is of a more in-depth quality in this mode of communication, particularly as it was a one-off interaction. I currently work in a therapeutic capacity using both modes of communication and I feel face-to-face working allows me to engage on a different and deeper level with my clients and I felt the same within the process of the

research interviews too. As a Counselling Psychology clinician, precedence is also set for interacting this way and it therefore felt more natural, at least for myself, for the interviews to be conducted this way, and particularly because of the sensitive nature of the topic area.

It could also be argued that physical presence creates a different effect, particularly with a sensitive topic area such as bereavement. For example when people were upset when the interaction was face-to-face it felt 'easier' to deal with because there were additional visual, non-verbal cues to read. This assisted in aspects such as gauging time to allow for silences and for processing on the participants part, much like in the therapy room.

I also feel that generally my interviewing technique could have been improved a lot and that with more time perhaps I could have spaced the interviews out more and spent more time developing my interviewing technique, particularly between the pilot and the first interview. There was also an overarching fear that participants might be 'lost' if I did not interview them soon after they had made contact, particularly as the sample is quite a specific one.

A lack of probing further into participant material was also an issue. This may have been due to some subconscious mechanisms; for example I did not probe further into what feeling one had lost a part of oneself was like for the participants, or what the phrase really meant. Perhaps this was because I had read about this notion in the literature, which had clouded my sight, and I stopped there, perhaps feeling I had found out what I thought I needed to. It

would have been interesting to see what would have come up with further exploration, and whether this would have resulted in similar ideas or not. It could be an interesting avenue for future research.

Finally, one must acknowledge one's own attitude to the research topic. Death is the only certainty in life, and our cognitive capacity as human beings results in an awareness of this and of our own mortality (Wong, 2000). I have reflected on a number of ideas, including attachment and loss and personal meanings for me, my own sibling bonds, and the fact that loss could have been considered in lots of different ways. I feel that something about the inevitability and finiteness of death contributed to the topic becoming something personally important for me to explore. I have also considered that perhaps part of this choice forms part of a subconscious desire to find some answers to, or console the self about, an ambivalence on reflecting that I will experience loss but never experience the pain of the loss a twin might have to feel (if it is indeed true that co-twin loss is the most painful type of loss one can experience). I also feel that the importance of the topic area for me grew throughout the research process, particularly as I became an aunt to fraternal twins during it. This conjured up very mixed feelings for me, including a deep sadness that the bond I see growing between my own fraternal twin niece and nephew may mean that one day they experience pain to a degree that some of the participants have reported experiencing. However I also take some comfort from the way in which my participants' accounts have enlightened me, made me more knowledgeable and motivated, and woken further a desire in me to share knowledge of this topic area with others, in the hope that bereaved twins can be helped further therapeutically.

Without being a twin myself, it is impossible for me to fully appreciate the impact of co-twin loss. However conducting the research and immersing myself in participants' accounts have helped provide me with greater understanding of the experience and also changed the way I think about it, as inevitably I carried some preconceived ideas about co-twin loss before embarking on the research. Some of these have been mentioned previously in reflexivity within the methodology chapter.

The aim of outlining these ideas is to help develop an understanding of the processes that contributed to the current study in order to increase its trustworthiness and integrity (Maso, 2003).

4.7 Avenues for Future Research

This research has begun accessing the experience of losing of an MZ co-twin in older adulthood but more knowledge is required of this experience and its impacts. It may also be useful to explore further the means by which twinless twins can continue the bond with the deceased co-twin, since this study suggests that they may need to move forward with or alongside their deceased co-twin, but has not been able to explore how this might be achieved.

Future research may also consider the inclusion of more male identical twinless twins. This lack was noted in Macdonald's (2002) study but was not successfully achieved in the current study. An interesting point to note arising in this study is that, while there was only one male participant, this participant seems to have been the only one to experience a more marked separation and individuation from his co-twin, and to

have apparently lived as a single person to a greater degree once married and have led his own life. It would therefore also be interesting to explore whether gender differences arise in how co-twin loss is experienced, and to look at this across different types of twinning.

A further future step may also be to explore the loss experience among DZ twins and examine how it may potentially differ. One particular point that comes to mind is the fact that DZ twins' physical resemblance will be less striking and similar than MZ twin pairs, and that therefore the sense of self and the loss experience may differ for DZ twins. Further into the future, others might consider other types of twinning but in particular the experiences of conjoined twins, as embodiment was a theme highlighted in the current study that may be experienced across other dimensions, including the physical attachment that is present among conjoined twins.

Furthermore, it might be interesting to investigate whether cause of death is linked to the way the grief is experienced. For example if the co-twin died in a peaceful way, does it mean that the remaining twin may be less likely to experience the violent dimension of embodied grief? This is not something that was explored or definitively seen in the current study; it is rather an afterthought that has arisen, but existing literature has documented that, for example, parents' bereavement experiences of the loss of a child through suicide are different from those of a non-suicide death (e.g. Murphy, Braun, Tillery, Cain, Johnson & Beaton, 1999). Comparisons could then also be made with co-twin loss and the same causes of death, to see whether differences arise across relationships.

Chapter Five: Conclusion

This research has taken a hermeneutic-phenomenological approach and illustrates a move away from the realist tradition that dominates co-twin bereavement research. The approach taken is also reflected in the choice of IPA as the favoured methodology.

Although the study may have some limitations, it has produced some interesting findings relevant to Counselling Psychology. Bereavement and grief are major topics within the field of Counselling Psychology and this therefore, inevitably means that a proportion of Counselling Psychologist's clients will have undergone bereavement, since some of us will require therapeutic support in relation to these experiences. In addition, multiple births are on the increase, so practitioners are also more likely to come into contact with bereft twins who have lost their co-twin (Withrow & Schwiebert, 2005).

As a review of the existing literature indicates, studies on co-twin loss have mainly focussed on quantitatively trying to measure aspects of grief and intensity of grief (e.g. Segal et al., 1995 and Segal & Ream, 1998), and these studies have suffered from questionable reliability and validity, as discussed in the literature review. These studies can neglect the diversity and complexity of individual experience and how this is embedded in our personal and social worlds (Smith & Osborn, 2008), and can also neglect the complexities (Stroebe et al. 2003) and uniqueness of grief. The analysis has highlighted that a qualitative approach can complement the existing quantitative research by exploring the phenomenon in a different way and revealing different insights into co-twin bereavement. This helps to add depth to the existing quantitative

bereavement research and broadens our understanding of bereavement more generally (Stroebe et al., 2003).

This research supports the findings from existing quantitative studies that co-twin loss is experienced as worse than other relationship losses. It also supports Macdonald's (2002) findings about the twinship and feelings of being a unit. The results also support more contemporary continuing-bonds research, where it is felt that a continuing relationship with the deceased is adaptive (Klass, Silverman & Nickman, 1996). However, where the current research departs from this is in its specificity in relation to the co-twin relationship. The findings in the current study perhaps suggest that there is a need for the bereaved to have a continuing relationship with the deceased co-twin, in which they move on alongside them or move forward with them in some way. It would be useful for further work to explore in what ways this might take place. The research may also suggest that regarding grief in general, many factors may influence the experience of it, such as relationship to the deceased, culture and society. It also suggests that identity is affected by bereavement and that grief can be experienced in an embodied manner, as seen in existing literature.

Overall, this study has illustrated that perhaps twinless twins need to move on with their deceased co-twins. This helps us understand the experience of the loss of a co-twin and may inform us on how this type of loss is thought about, and what to focus on in our therapeutic work with this client group. What has been most prominently highlighted in this research is a thread about embodiment running through participants' accounts. This is seen in the relationship prior to loss, for example where some participants described feeling connected to each other. It is also seen in the loss

manifesting and managed in the body, particularly in painful and violent ways, and in the preservation of a connection with the co-twin, which can be thought about in an embodied manner in the sense that ideas about keeping a part of the self 'alive' are present. These perspectives on embodiment in grief and the relation of this to identity, have proved to be the most striking aspects of this study.

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Appendix One: UEL Ethics Approval

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Kendra Gilbert

ASSESSOR: Ian Well

STUDENT: Miriam Dookhun

DATE (sent to assessor): 08/10/2012

Proposed research topic: An exploration of the experience of the loss of a co-twin, for surviving identical twins: an interpretative phenomenological analysis.

Course: Professional Doctorate in Counselling Psychology.

1. Will free and informed consent of participants be obtained? **YES / NO**

2. If there is any deception is it justified? **YES / NO / N/A**

3. Will information obtained remain confidential? **YES / NO**

4. Will participants be made aware of their right to withdraw at any time? **YES / NO**

5. Will participants be adequately debriefed? **YES / NO**

6. If this study involves observation does it respect participants' privacy? **YES / NO / NA**

7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? **YES / NO / NA**

8. Is procedure that might cause distress to participants ethical? **YES / NO / NA**

9. If there are inducements to take part in the project is this ethical? YES / NO /
NA

10. If there are any other ethical issues involved, are they a problem? YES / NO /
NA

APPROVED

YES	YES, PENDING MINOR CONDITIONS	NO
------------	----------------------------------	-----------

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: IW Date: 29/11/12

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Kendra Gilbert

ASSESSOR: Ian Well

STUDENT: Miriam Dookhun

DATE (sent to assessor): 08/10/2012

Proposed research topic: An exploration of the experience of the loss of a co-twin, for surviving identical twins: an interpretative phenomenological analysis.

Course: Professional Doctorate in Counselling Psychology.

Would the proposed project expose the researcher to any of the following kinds of hazard?

- | | | |
|----|-----------|-----------------|
| 1 | Emotional | YES / NO |
| 2. | Physical | YES / NO |
| 3. | Other | YES / NO |

(e.g. health & safety issues)

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

APPROVED

YES	YES, PENDING MINOR CONDITIONS	NO
-----	----------------------------------	----

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **IW** Date: 29/11/12

Please return the completed checklists by e-mail to the Helpdesk within 1 week.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London
www.uel.ac.uk

School of Psychology
Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,



Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



EXTERNAL AND STRATEGIC DEVELOPMENT SERVICES

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Quality Assurance and Enhancement



20 March 2015

Dear Miriam,

Project Title:	An exploration of the experience of the loss of a co-twin, for surviving identical twins: an interpretative phenomenological analysis.
Researcher(s):	Miriam Dookhun
Principal Investigator:	Kendra Gilbert
Reference No:	AMD 1415 08

I am writing to confirm that the application for an amendment to the aforementioned research study has now received ethical approval on behalf of University Research Ethics Committee (UREC).

Should any significant adverse events or considerable changes occur in connection with this research project that may consequently alter relevant ethical considerations, this must be reported immediately to UREC. Subsequent to such changes an Ethical Amendment Form should be completed and submitted to UREC.

Approved Research Site

I am pleased to confirm that the approval of the proposed research applies to the following research site.

Research Site	Principal Investigator / Local Collaborator
Locations of participants' choosing, plus Skype and telephone	Kendra Gilbert

None of the approved documents have changed.

Summary of Amendments
Change of participant recruitment criterion to those who have lost a twin 2 or more years ago (from the original 5 or more years ago).
Use of Skype and telephone for some of the interviews

Ethical approval for the original study was granted on 29 November 2012.

Docklands Campus, University Way, London E16 2RD
Tel: +44 (0)20 8223 3322 Fax: +44 (0)20 8223 3394 MINICOM 020 8223 2853
Email: r.carter@uel.ac.uk



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Quality Assurance and Enhancement



Approval is given on the understanding that the UEL Code of Good Practice in Research is adhered to.

With the Committee's best wishes for the success of this project.

Please ensure you retain this letter, as in the future you may be asked to provide evidence of ethical approval for the changes made to your study.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Prof Neville Punchard', is written over a light blue rectangular area.

Professor Neville Punchard
Chair
University Research Ethics Committee (UREC)
Email: researchethics@uel.ac.uk

Docklands Campus, University Way, London E16 2RD
Tel: +44 (0)20 8223 3322 Fax: +44 (0)20 8223 3394 MINICOM 020 8223 2853
Email: r.carter@uel.ac.uk



Appendix Two: Research Proposal Approval from Department of Twin

Research

RE: Research Proposal -E344

Vazquez, Victoria

Victoria.vazquez@kcl.ac.uk

Mon 25/02/2013 08:25

To: Miriam Dookhun (miriamdookhun@hotmail.co.uk)

Cc: Clement, Gail (gail.clement@kcl.ac.uk)

Dear Miriam,

Apologies for the delay in getting back to you. The project has been approved. Gail Clement will liaise with you further with regards to the ageing criteria for the twins required for your project.

Thank you

Best Regards

Victoria

Appendix Three: Information Sheet

University of East London

Department of Psychology, Stratford Campus, Water Lane, London, E15 4LZ

University Research Ethics Committee

If you have any queries regarding the conduct of the study in which you are being asked to participate, please contact the Secretary of the University Research Ethics Committee, Ms Debbie Dada, Admissions and Ethics Officer, Graduate School, University of East London, Docklands Campus, London E16 2RD (Tel 020 8223 2976, Email: d.dada@uel.ac.uk)

The Principal Investigator(s)

Miriam Dookhun – Trainee Counselling Psychologist
University of East London, Department of Psychology, Stratford Campus, Water Lane, London, E15 4LZ

Telephone number: 07706290906 E-mail: u0928278@uel.ac.uk

As a trainee counselling psychologist I am trained to deal with sensitive issues and I have regular supervision and personal therapy sessions.

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study. The study is being conducted as part of my Counselling Psychology Doctorate at the University of East London

Project Title

An exploration of the experience of the loss of a co-twin in adulthood, for surviving identical twins: an interpretative phenomenological analysis.

Project Description

The aim of the study is to explore what the loss of your co-twin was like for you, through a flexible interview.

Participants are required to describe the loss and what it was like for them and how this impacted upon them, and this may involve covering topic areas such as what emotions and experiences it brought up for them.

Participants will be asked to speak freely and in some detail if they can, about their experience of the loss of their identical co-twin.

Speaking about the loss of their co-twin may bring up unwanted and uncomfortable feelings for participants and these may remain with the participant after the interview. Due to this some aftercare may be required for some participants. All participants will be provided with contact details of national, recognised organisations that support those who have suffered a loss and also those that have specifically experienced co-twin loss.

It is hoped that through being involved in the study, participants will provide some insight into what the death of a co-twin is like for the surviving identical twin.

Confidentiality of the Data

Data collected will be stored on a password-protected laptop. To protect the data's confidentiality, printouts will include pseudonyms and details that may identify participants will be altered in the write-up.

Ten years after the project has been passed and the programme of study has been completed, data will be destroyed by shredding papers, permanently deleting computer files and wiping audio-recorded data.

Location

Interviews will be carried out at the Twin Registry at St Thomas' Hospital, London, at the University of East London, or at participants' homes.

Remuneration

No payment will be made for participation.

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason however, please note that unless otherwise stated by you that you do not wish so, the researcher may retain and use any data collected before this. Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

Thank you in anticipation. Yours Sincerely, Miriam Dookhun (November 2014)

Appendix Four: Informed Consent Sheet

Consent to participate in a research Study

An exploration of the experience of the loss of a co-twin in adulthood, for surviving identical twins: an interpretative phenomenological analysis.

I have the read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. The researcher involved in the study will have access to the data and that will remain confidential and the anonymity of my data will be protected. It will be stored on a password-protected laptop that only the researcher has access to. An organisation external to the university may have access to the data purely for transcription purposes and this organisation will also be bound by these confidentiality rules. I consent to and understand this, and that they will also be asked to sign a formal agreement about this. The audio recordings of the interviews will be transferred straight to the password-protected laptop from the dictation machine, printouts will include pseudonyms, and details that may identify me will be altered in the write-up. Any named information will be kept separate to my data. It has been explained to me what will happen once the experimental programme has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

Participant's Signature

Investigator's Name (BLOCK CAPITALS)

Investigator's Signature

Date:

Appendix Five: Debrief Sheet

Thank you for taking the time to participate in the study. Your contribution is invaluable to the research.

Some people may feel some emotional discomfort because of the nature of the topic discussed. If so, you may want to contact an organisation for some support, below are details of some organisations you may find useful:

- **Cruse Bereavement Care**
Telephone Number: 0844 477 9400
E-mail Address: helpline@cruse.org.uk
Website: www.crusebereavementcare.org.uk
- **The Compassionate Friends**
Telephone Number: 0845 123 2304
Website: www.tcf.org.uk
- **The Lone Twin Network**
E-mail Address: info@lonetwinnetwork.org.uk
Website: www.lonetwinnetwork.org.uk
Postal Address: Lone Twin Network
54 Ventnor Avenue
Hodge Hill
Birmingham
- **The Samaritans**
Telephone Number: 08457 90 90 90
Email Address: jo@samaritans.org.uk
Website: www.samaritans.org
- **Twinless Twins**
E-mail Address: uk@twinlesstwins.org
- **Twins UK**
Website: <http://www.twinsuk.co.uk/twinstips/24/133/loss--bereavement-/surviving-the-loss-of-a-twin-or-co-multiple/#>

Below are also reading materials on the subject matter that you may be interested in:

- Woodward, J. (1998) *The Lone Twin: Understanding Twin Bereavement and Loss*. England: Free Association Books.
- Sandbank, A. (1999) *Twin and Triplet Psychology: A Professional Guide to Working with Multiples*. USA: Routledge.

Appendix Six: Table of Overview of Age Ranges in Some Existing Studies on Co-twin, Sibling and Spousal Loss

	Death-how long ago?	Type of death	Age at death
Golsworthy (spousal loss)	1-3 years ago	Suddenness of death was variable	Surviving partner 50+
Bonanno (spousal loss)	18months ago		27-74 years
Carnelly (spousal loss)	A few months-64 years ago		
Khosravan (spousal loss)	1-15 years ago		20-48 years
Lee (spousal loss)	Not part of recruitment criteria	Death from cancer illness	Not part of recruitment criteria
Kaunonen (spousal loss)	6 months or more		25-65 years
Daggett (spousal loss)	8 months – 6 years ago		41-54 years
Limor (sibling loss)	‘In adolescence’		‘Adults’
Pike (Sibling loss)	At least 5 years ago		18-31 years
Coles (sibling loss)	At least 3 years ago		Early adulthood
Charles and Charles (sibling loss)	Throughout the lifetime		
Worden (sibling loss)	2-13 months ago		2 months-20 years
Rodger (sibling loss)	1 year ago		20-27 years old
Sundar (sibling loss)	2-4 years ago		18-30 years old
Miles (sibling loss)	5 years ago or more		4-16 years old
Segal and Ream (co-twin loss)	0-45 years		15-79 years old
Segal et al. (co-twin loss)	0-45 years		15-87 years

Appendix Seven: Final Interview Schedule

- 1) Can you tell me a bit about the person you lost and what happened?
(Possible prompts: What was your twin like? What was their character like?)
- 2) What was your relationship like with your twin?
(Possible prompts:
How did you feel about your twin status/twinship/twin bond? What was it like?
Did you dis/like being a twin?-In what ways did you dis/like it? What aspects made you dis/like it?)
- 3) What was your experience of your twin relationship prior to the loss of X?
- 4) What was it like when you lost X? At the time? After? Now?
(Possible prompts: What did you feel? Think?)
- 5) What did being a twin mean to you?
- 6) How did the loss of X impact on you?
(Possible prompts: What's different in your life now? Has it changed the way you see yourself? [Identity])
- 7) What is your relationship with your twin now?
(Possible prompts: In what way? Spiritual/Religious Connection? → different impacts – do you think you will see them again? Are they still with you? [Continuing bonds], coping mechanism e.g. diaries?).

Appendix Eight: Pilot Interview Schedule

1) When did you lose your twin?

(Possible prompts: How many years ago? How old were you?)

2) What was your relationship like with your twin?

(Possible prompts: How did you feel about your twin status/twinship/twin bond, what was it like? Did it you like/dislike being a twin? What aspects made you dis/like it? In what ways did you dis/like it?)

3) How did you lose your twin?

(Possible prompts: Circumstance of loss; illness? Suicide? Accident? Unexpected/sudden/expected?)

4) Has losing your twin had any impacts on you?

(Possible prompts: In what ways? How did you feel when you lost your twin? How do you feel now? Has the loss of your twin changed the way you see yourself (before vs after)? How do other people see you? - your family members, friends? Do they think you have changed?)

Appendix Nine: Example of Part of an Interview Transcript

Punctuation has been used in the following manner in the transcripts: commas have been used for short pauses and repeated dots have been used for longer pauses.

- 1 I: Right, so if you could J, start maybe start by telling me a bit about R um and what happened
2 J: Er, do you mean at the accident or when we were young?
3 I: Wherever you might like to, to start
4 J: Yes, well, we were, we were identical twins
5 I: Mhm
6 J: And er, we were always together, as children, always dressed the same, my mother used to say, you are
7 something together and nothing parted..and er, we, we slept in, we slept in the, together, in the same bed
8 I: Mhm
9 J: For nearly thirty years
10 I: OK, uh-huh
11 J: We were, were that close
12 I: Yes
13 J: Except when we went into the army and we had separate beds..erm, we went through all our, childhood
14 experiences together, we started school together
15 I: Mhm
16 J: We cried together because we thought that we could not do our sums
17 I: Oh
18 J: And er, we, we joined the Boys Brigade together
19 I: Mhm
20 J: And er the Cubs together, we even fell out over the same girls (smiles)
21 I: (Laughs)
22 J: So, so er..and er we were very much er a pair and er, we were always well liked and er..well, I do not know..
23 how to carry on from there, um..I remember a, a girl saying, the twins..the twins er were nice lads and she
24 used to say I do not know which one I, I would take out (smiles)
25 I: (Laughs)

26 J: So we were both, we were both very much like each other
27 I: Uh-huh, OK, so very very alike. If you had to um, if you had to describe R, how would you describe him?
28 J: R?
29 I: Mm
30 J: Well, well apart from the fact that we were like each other, R was a good stone heavier than me
31 I: Mhm, OK
32 J: Er, he, he once, he once went onto a programme of drinking..Jersey Milk..and from that time onward he got a
33 fatter face, fuller face
34 I: OK
35 J: Er, R was um..the difference in our, we had a difference in our personalities, R tended to be aggressive
36 I: Mhm
37 J: I tend to be, I tended to fit in with him. There is, when there is two that come together, there is one that has
38 got to give
39 I: Mhm, mhm
40 J: And so I used to give into R and R used to take the lead, lead and I describe it this way, if there was a, an
41 enemy aircraft that was going to bomb our house
42 I: Mhm
43 J: R would be in the front yard, building an anti-aircraft gun
44 I: Yes
45 J: And I would be in the back, building an air-raid shelter
46 I: OK, uh-huh
47 J: So that is our, that is our difference....erm, R was a little bit er brighter than me, er if we, if I did well at
48 school and got seventy marks
49 I: Yes
50 J: And was proud of myself, R got seventy-two, so whatever we did I always felt a failure
51 I: OK, so, would you, would you say that, was that, would you describe that in words, terms like maybe
52 competition? Or something else?
53 J: Er, yes, you see when you, when you are living with someone, that is similar to you, like you
54 I: Mm
55 J: You are an easy subject for, for um, comparison
56 I: Mhm mhm
57 J: And this is the destructive thing about being a twin, er, you cannot, you want to be yourself

58 I: Mhm
59 J: And er, when we got married, that was my opportunity to be myself
60 I: OK
61 J: Once that kind of umbilical cord has broken..and er my wife er identified this and she was always annoyed
62 when R came to visit me because I went back, I regressed into this, style of being..the follower instead of the
63 leader
64 I: Mhm
65 J: And that used to annoy my wife tremendously and I did not realise it, but now I can, now that she has
66 mentioned it I could see, that um, I sort of blossomed more when I was..when we were living our own lives
67 I: Mhm
68 J: When R er..we were so much alike and so..close to each other, for the first six months my wife, I was
69 married first, and um we lived, we went to live in our home, until we got our own house built...
70 I: Mhm
71 J: ..And the bed, R had to find a, a, a, a bed of his own, and er I was so thrilled at getting married, that I never
72 asked him if that was..if I could got..could get his permission to use the bed that we used
73 I: Uh-huh
74 J: And he always resented that, I could, that came back to me years later, but er I just took it for granted that my
75 wife and I would be taking the double bed
76 I: Mhm mhm
77 J: And er and so, erm...I think, I think you could understand that when two people are so close together and a
78 third one comes in and interrupts the party
79 I: Mhm
80 J: There is this natural resentment
81 I: Mhm. How did, how did you feel in that though?
82 J: Well, I did not feel the resentment you see
83 I: Mhm
84 J: I was the one that was having a good time
85 I: Yes, yes
86 J: It was my brother that felt the resentment
87 I: OK
88 J: Um, I know, I know when R, he was the first, to court, a girl
89 I: Mhm

90 J: And he used to come home to me and tell me ‘Oh, oh what do you think of A? Oh Isn’t it wonderful that I am
91 courting’, and, and he used to say ‘Oh I feel grand when we are linking each other’ and, and I can hear the
92 clip-clop of her high heels and he used to me all about this and it used to annoy me
93 I: Mhm
94 J: Because I had not had his experience, and I can remember when they both fell out I did not offer him any
95 sympathy, I said ‘Oh shut up! I am, I am, I am sick of you talking about your girl,’ even when he had fallen
96 out, you see
97 I: Mhm
98 J: Which is a very cruel thing for me to do, but I was relieved! That at least he was not going to come and, and,
99 and tell me what good times he had had
100 I: OK
101 J: So that was the relationship we had, it, it was almost as if a new person had come into our, in between us
102 and I resented it
103 I: Mhm, so was it a similar kind of feeling, do you think, when you got married, he felt that
104 J: Yes!
105 I: Way
106 J: Yes, exactly the same
107 I: Mhm, mhm
108 J: Yes exactly the same, I can understand it all now
109 I: Yes
110 J: That I am older, like I do not feel offended by it all
111 I: Mhm
112 J: But um that is er, that is the disadvantage of being an identical twin
113 I: Mhm
114 J: There are tremendous advantages, because, you are almost like a film-star, everybody looks at you
115 I: Mhm
116 J: When I was in the, when we both went into the army we, R and I used to, used to have a, a, a, erm..a private
117 joke, we used to say, ‘Now, I wonder how long, these people are going to take, to realise we are twins’, if
118 we went into the canteen and sat down on the table with about six people
119 I: Mhm
120 J: We used to say ‘I wonder how long they are going to start to snigger’ and sure enough you know, one of
121 them would say ‘Hey! Are you twins!?’ , you know and we would, we would nudge each other

122 I: Mhm
123 J: And er I can remember once going to the um hairdressers..and R had gone the day before, and I went in, er..
124 and as soon as he saw me he said 'Excuse me sir, did I do it alright yesterday? Did I, did I do anything
125 wrong?', so I had to tell him that er 'Oh, er this is the first time I am here!'
126 I: Mhm
127 J: Er, I am, we are identical twins and, and that is (inaudible), he thought I had come back to get, you know,
128 um, so no we, we used to have a joke
129 I: Yes
130 J: At school, we were so alike
131 I: Mhm
132 J: That people would come to me and say 'Are you you or your brother!?' (Smiles)
133 I: (Laughs) Yes
134 J: And I, if I, if I was given a silly question, I gave them a silly answer!
135 I: So what did you say?
136 J: I used to say, I used to say 'I am my brother, I am not me I am my brother!' (Smiles)
137 I: (Laughs)
138 J: So er no we had er, we did have a, a good, we were brought up in a, in a Christian home
139 I: Mhm
140 J: Very loving mother and I hope when I give my testimony anywhere, when I am at church and I have to get
141 up and express my faith
142 I: Mhm
143 J: I always say there is two things I am always really grateful to God for, one was I was brought into the world
144 by a very, very godly..mother
145 I: Mhm
146 J: And the second thing is I was born an identical twin
147 I: Mhm
148 J: So I mentioned the disadvantages, but the advantages far outweighed the disadvantages
149 I: OK uh-huh. What other advantages um, do you feel that there were?
150 J: Say that again
151 I: What other advantages do you feel that there were of being an identical twin?
152 J: What other things have, have I got to say about being a twin?
153 I: What other advantages do you find that there were?

154 J: Sorry, now I, cannot catch what you are saying
155 I: I was just asking what advantages, what other advantages are there?
156 J: Oh..what other advantages, erm..well the, the, the biggest one is you are always, you are always erm, this, it,
157 it is like being a film-star in a way
158 I: Mhm
159 J: You know you are always, you are always, um, noticed
160 I: OK, uh-huh
161 J: And er, if you are, if you are, if you are an outward-going person, well that is er, that is acceptable, if you
162 are shy it is not acceptable but, but I had no problem with it
163 I: OK
164 J: Erm, if we were walking up the, up the town, er, we would, we would see, er people, smiling at us
165 I: Mhm
166 J: Things like that, that, that is a tremendous advantage I think, er you will, you are always, you are always
167 remembered
168 I: Mhm
169 J: At school, there, there, I used to er, I used to, er maybe thirty years or forty years afterwards, I would
170 recognise somebody and er 'Oh yes' they would say, 'You, there was two of you wasn't there' and that, that
171 made us easily recognisable
172 I: Mhm and how did that make you feel?
173 J: Oh it, it, I was always, I was, I always thought it was a compliment to be like R
174 I: Mhm
175 J: I always admired R..and I, I think he always admired me..erm, we were both very, very shy, when we were
176 young
177 I: Uh-huh
178 J: In- incredibly shy, and er, we felt a, a sense of inferiority, and it took a long time for us to get over that..um..
179 but we, we, you know as you get older you do, lose these personal pains
180 I: Mhm, mhm
181 J: And er..I only wish I, had, the, maturity, now, that that I er had then what I have, what I have now
182 I: Mhm. When you talk about the inferiority
183 J: Yes
184 I: Can, can you tell me a bit more about that, in what way did you feel inferior?
185 J: Yes, well, well I got my inferiority because I did not do well at school

186 I: OK
187 J: I did not, I did not pass my exams, and it was at the time when you sat the, the um, what they called, the
188 merit, the eleven-plus exams
189 I: Mhm
190 J: And er we did not pass it, neither of us passed it, erm I think, I think er, erm an educationalist would say that
191 we were late developers
192 I: OK
193 J: And er, I used to get, I used to feel so inferior when I saw, grammar school boys..at work, you know and
194 taking their grammar school scarves off
195 I: Mhm
196 J: And that made me feel very, un, un, uncomfortable, it was very sad that..um..I think that was the basis of
197 my feeling of inferiority..and it took quite a long time for me to lose it
198 I: OK, mhm
199 J: Because now I realise that, you do not have to be clever to do well at, in life
200 I: Mhm
201 J: You can do well, erm, without, er, being, er, having twelve GCE's or
202 I: Mhm
203 J: Or a degree
204 I: Yes
205 J: It is not, it is not vital
206 I: Yes
207 J: You can get by and have a, a successful life without it
208 I: Mhm
209 J: But that, at that stage, everything was how many school certificates have you got..well I was, I remember
210 going for a job..and er the chap said er..‘How many Ordinary school, certificates have you got?’ I said ‘I
211 have not got any’, ‘No, how many Advanced school certificates have you got?’ I said ‘I have not got any’,
212 and then he, he leaned forward from his chair and said ‘How many Ordinary school certificates have you
213 got?’ I said ‘I have not got any’ and then he nearly (laughs)..he nearly fell off the chair, he said ‘Which
214 school did you go to?’ I said ‘I went to an ordinary, elementary, school’ and at that point he lost interest in
215 me
216 I: Mhm
217 J: So you can soon see how you can develop a complex

218 I: Yes
219 J: Because you feel as though you are on the scrap-heap..but er, er despite that, er I did well er in my job, I got
220 all the exams that I could get, I have got letters after my name
221 I: Mhm
222 J: I was a registrar of births, deaths and marriages
223 I: Oh wow
224 J: So, so you do develop
225 I: Yes
226 J: As you get older
227 I: Yes, yes
228 J: And you get skills, and I have even passed exams that my grammar school pals have not passed (grins)
229 I: (Laughs)
230 J: So er, and R was the same
231 I: Uh-huh
232 J: R's done well, R was an accountant
233 I: OK
234 J: And er very very capable accountant too, so, we managed to get over the..the, in that the, bad start that we
235 had
236 I: Mhm
237 J: As children
238 I: Mhm mhm and when you, when you think about your, um, I suppose your, your twin relationship with, with
239 R, the, maybe, we might term it the 'twinship' sometimes, um, how did you feel about that?
240 J: Well, we were both, we both felt very honoured
241 I: Mhm
242 J: To be brought into the world, as identical twins
243 I: Mhm
244 J: Despite the fact of the drawbacks..erm, it is rather like marriage, I do not, are you, I do not know whether
245 you are married or not
246 I: No, no I am not
247 J: But er, but erm...married life has some wonderful benefits, but it also has drawbacks
248 I: Mhm
249 J: Because you cannot really do what you want, you have got to please your partner you see

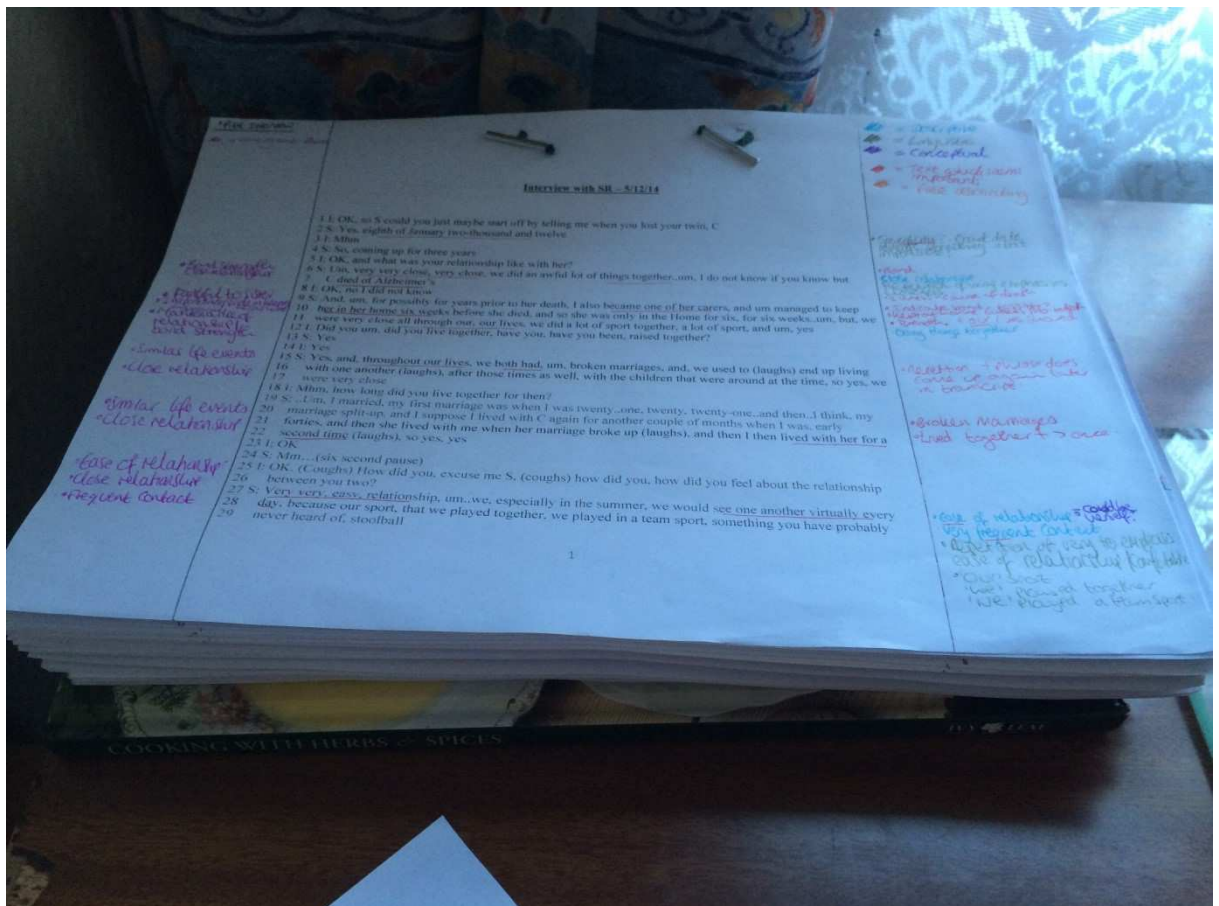
250 I: Mhm
251 J: So, so being an identical twin is a mixed blessing, like everything else today, it is mixed, but the advantages
252 certainly outweigh the disadvantages, I would not, I would not swap my place with anybody
253 I: Mhm
254 J: And we both er, had a very great respect for each other, right up to the very, very end.....so I do not know..I
255 am going to, I am waiting for you (smile)
256 I: (Laughs)
257 J: That lovely smile on your face!
258 I: (Laughs) Sure, sure OK let, let, let me, let me ask you something else then, um was there anything I
259 suppose, um, you have talked about advantages and disadvantages, but was there anything maybe that
260 you..well, I suppose you said a mixed blessing, anything else you, you disliked about being a twin?
261 J: About being a twin.....I do not think so, the big one was, that we are so easily compared
262 I: Mhm
263 J: And er..it, it was the fact that R was always that bit more success—, there was not much in it
264 I: Mhm
265 J: It was just a, it was just a mark or two
266 I: Yes
267 J: But it was a, it was a very irritating..gap
268 I: Mhm
269 J: But er, then I had, I developed skills that he did not have you see, and er, and so, it was er..it was a very
270 compensating thought, when I realised I could do things better than R
271 I: Mhm mhm, did you find then that it kind of balanced out, evened out, both sides
272 J: Yes yes
273 I: For both of you?
274 J: Yes, our skills did even each other out
275 I: Mhm mhm
276 J: Um...I think God gives everybody a gift, all gifts, and the, the er mature thing is not to compare yourself
277 with others
278 I: Mhm
279 J: If you start comparing yourself with others, then you will either become superior or inferior
280 I: Mhm
281 J: But if you compare yourself with yourself and see how you have developed through the years

282 I: Mmm
283 J: That seems to be the only way you can use the comparison skills
284 I: Mhm but do you think that being a twin makes that either easier, or more difficult?
285 J: Well it makes it easier to compare yourself with somebody else, that is the disadvantage...
286 I: As in to the, to your twin, or to other people...to your twin?
287 J: Yes, yes, it is you, it is you could ea-, R used to come to me and he used to say..erm, 'Did you enjoy that
288 meal you have just had?' we were, perhaps I was, and I would say 'Yes,' well he said 'I enjoyed it,' or if we
289 were watching a television programme
290 I: Mhm
291 J: He would say 'Did you enjoy that programme?', we usually did enjoy the same things
292 I: OK mhm
293 J: Er, we were both, both er, er..keen Christians
294 I: Mhm
295 J: Er..we were both keen on documentary films
296 I: Mhm
297 J: Anything informative, we are not so keen on novels, we, we, we loved to read textbooks
298 I: Mhm
299 J: Anything that is informative, we both loved those
300 I: So you had very similar likes?
301 J: Very similar likes
302 I:Mhm
303 J: Yes, dislikes, yes
304 I: Yes
305 J: Very similar
306 I: Mhm, OK
307 J: Erm...and he expresses himself pretty much the way I do
308 I: Uh-huh OK, uh-huh, OK
309 J: We both have the same political views, erm...so we are similar in more than looks
310 I: Yes
311 J: We were similar in our er attitude
312 I: Mhm

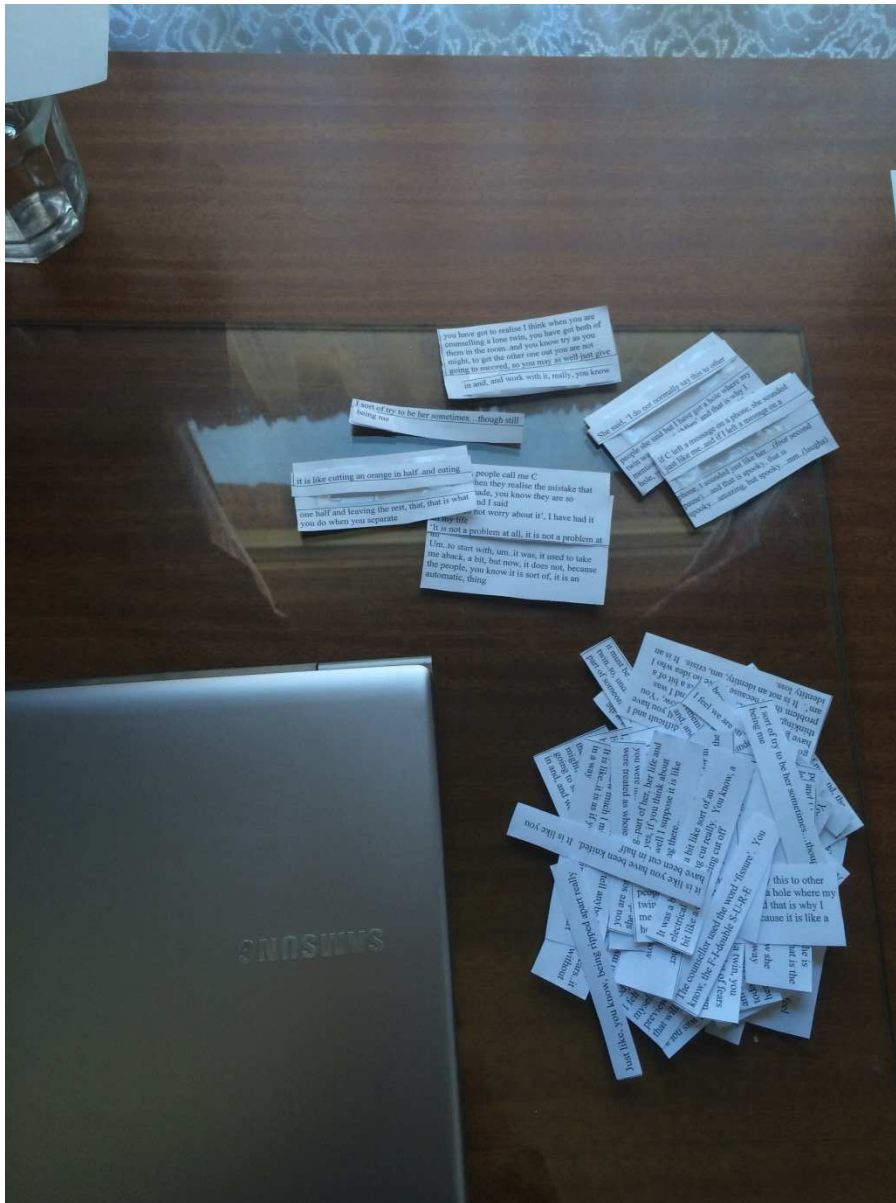
Appendix Ten: Example of Process of Theme Generation

Small-margin on the right for anything of interest and initial thoughts and comments including parts that captured attention, speculations and associations and then more interpretative notes on how and why participants had these concerns, included examining language used, particularly metaphors in the current study.

Left-hand margin – potential themes drawn out from the initial notes made and were words or phrases that reflected both the participant’s words and subsequent interpretations made from examining them.

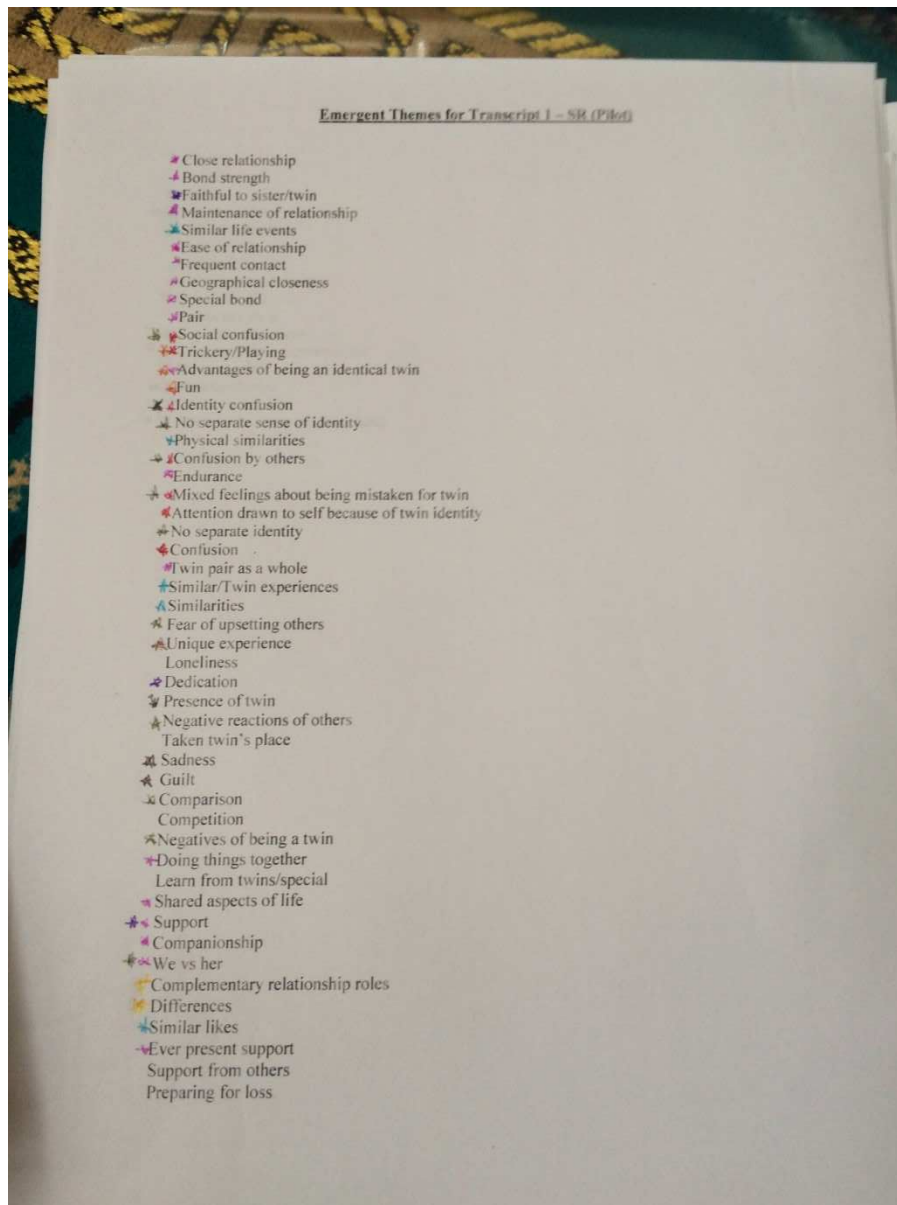


Clustering of themes



Potential themes were printed onto sticky strips of paper to enable ease of movement for grouping and re-grouping.

Feeling somewhat overwhelmed by the vast number of initial themes I began with and after initial attempts at grouping them, I moved on to using lists and colours for further grouping.



After this, I reverted to using sticky bits of paper to re-group themes further, reflecting the iterative nature of IPA (Smith et al., 2009), in a number of ways.

From this I then thought in a broader sense about the ideas the groups of themes were capturing, in order to help generate master theme labels.

Appendix Eleven: Example of Master Theme and Relating Subthemes with Supporting Quotations

Theme 1: The Twin Relationship

<u>Subthemes</u>	<u>Quote</u>	<u>Transcript, Page Number, Line Number</u>
‘You are a Part of Each Other’	<p>You know, she, she is there (Mhm) You know, she is part of, part of you</p> <p>it is not a sister, it is part of you, you are part of each other</p> <p>she was, not just his, sister in law..she was the other half of me...she was the other half of me</p>	<p>Esther, p.28, lines 880-882</p> <p>Esther, p.14, line 418</p> <p>Eleanor, p.42, lines 1328-1329</p>
‘We were always just called “twinny” ’	<p>you were not treated as an individual, you were treated as whole</p> <p>at school you are always treated as a “twinny”</p> <p>You are one of “the twins” (OK) or “the twinny”</p> <p>Yes, in fact we were always just called “twinny”, rather than by our Christian names (Mhm) It was just “twinny”</p>	<p>Maria, p.10, lines 304-305</p> <p>Maria, p.9, line 286</p> <p>Maria, p.10, lines 292-294</p> <p>Sarah, p.3, lines 76-78</p>

	<p>right up to then, we were still “The P twins”, weren't we?</p> <p>She always referred to us as “The Twins” she never referred to B and JY (Mhm) It was always “The Twins”</p> <p>Because you are, you have been referred to as “the twins”, particularly if you were brought up like I was</p> <p>At school, there, there, I used to er, I used to, er maybe thirty years or forty years afterwards, I would recognise somebody and er ‘Oh yes’ they would say, ‘You, there was two of you wasn’t there’</p> <p>People would come to me and say ‘Are you you or your brother!?’</p> <p>You are almost like a film-star, everybody looks at you</p> <p>Actually my mother was so proud of having twins</p> <p>And he used to take us to see our grandmother, which was his mother (Mhm)</p>	<p>Eleanor, p.23, line 721</p> <p>Jill, p.4, lines 106-108</p> <p>Jane, p.12, lines 347-348</p> <p>Jack, p.6, lines 169-170</p> <p>Jack, p.5, line 132</p> <p>Jack, p.4, line 114</p> <p>Jill, p.4, line 99</p> <p>Eleanor, p.4, lines 98-112</p>
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	<p>Er, on a Sunday morning and we walked, and it was quite a distance but we walked with him. And he was the proudest man going, walking, to granny's (Mhm) Holding a twin on either side (Mhm) And people stopping him, he was as proud as punch my dad was (Laughs) And we, we used to say, "Come on dad, come on dad" (Laughs) Because people would stop and talk (Mhm) And they would say "Which one is this?" Or, or they would say, you know, "ES" to me and, and, or they would say "MP"</p> <p>And at school, we were so alike they tried to separate us but my mother would not allow it. They wanted to put us in different classes when were in the senior school (Mhm) And my mother would not allow it my mother used to sit, just sit and smile and she used to say you are just like looking in a mirror you two</p> <p>You are something together and nothing parted</p>	<p>Eleanor, p.2, lines 45-48</p> <p>Eleanor, p.7, lines 206-207</p> <p>Jack, p.1, lines 6-7</p>
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	<p>you two are useless apart but very strong together</p> <p>And we have a younger sister, three years younger and our birth, birthday parties, people would turn up with two presents, you would expect one for me, one for E. We got one</p> <p>(Mhm)</p> <p>SH got another and erm when we asked, “Oh well there is one for her, there is two of you, she might feel left out”</p>	<p>Janet, p.20, lines 589-590</p> <p>Alice, p.5, lines 133-137</p>
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